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The Meaning of Patient Involvement and Participation in Chinese Hospitals

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Abstract

Increased patient involvement and participation in health care is embraced by researchers and practitioners due to the benefits of improving health outcomes and safety, reducing cost and enhancing a democratic relationship between service providers and users. Patient preferences and views are regarded valuable in the delivery of health care. However, the meaning of patient involvement and participation, particularly the willingness for involvement, changes from context to context, depending on the positions or circumstances patients occupy. In addition, the meaning of patient involvement and participation is likely to be affected by wider contexts, such as meso-level and macro-level contexts. Yet, the association between the meaning of involvement and contexts has been underdeveloped in the literature. Although there are a range of studies exploring the determining factors of patients' desire for involvement at the clinical level and discussing the issue within a particular context, it needs a comprehensive and systematic analysis of political, policy, institutional, individual, cultural and social contexts. Meanwhile, as most of the previous studies focus on mature and publicly-funded health systems, it remains unknown what patient involvement and participation means in other health systems. In this regard, the study focuses on China, a new context with a non-publicly funded and developing health system, which provides a unique case to develop the new knowledge of patient involvement and participation. A fundamental question is addressed in the study: What does patient involvement and participation mean in Chinese hospitals?

To explore the taxonomy of patient involvement and participation and the contextualised factors that are likely to affect the willingness of service users in health care delivery, I adopt a three-case design with three local hospitals in Shandong Province, an eastern province of China. I use the abductive research strategy to generate emergent hypotheses in the first stage of fieldwork and test deductively in the second stage. Qualitative methods are used for data collection, including individual interviews and policy documents. Interviews involve a range of stakeholders, including service users, professionals, health board managers and local administrators.

The evidence in East China demonstrates that the macro-level and meso-level contexts play a crucial role in affecting users' willingness for involvement, including political, policy and institutional contexts, as well as economic and socio-demographic conditions. Marketisation and consumerism, professionalism, the absence of political participation and the limited development of civil society are all contributors to the willingness for involvement. The lack of policy support, the current institutional design of user involvement, different organisational autonomy and resources, and the demography of the population of service users significantly affect how much service users wish to be involved. Meanwhile, a range of individual contexts are identified to significantly affect how Chinese service users wish to be involved in their health care, including health insurance type, socio-demographic characteristic and disease-type. Cultural context and family influence also matter. The social capital, seriousness of condition and the stage of condition are likely to affect the demand for involvement. Through the lens of various stakeholders, I examine the barriers to patient involvement and participation in China and proceed to a further theoretical discussion of co-production in health care.

Lay Summary

In recent years, involving patients in their health care is greatly promoted by researchers, health professionals and policy-makers in many countries. Patients and their carers may come across many medical circumstances, such as getting information about illness, giving choices of treatments and making decisions. Involving patients is beneficial for improving health outcomes, saving costs of health services and increasing the power of patients and carers. However, a main problem is that some patients may wish to be involved in their health care, while others may not. Some are happy to know everything about their condition and exchange ideas with doctors. Some feel not confident enough to engage with doctors, as they perceive they know little of health care. Some feel stressed and would like others to make decisions for them. In addition, the broader context plays a key role in affecting how and to what extent people want to engage with their doctors, including policy, institutional and political contexts. So far, in some publicly-funded and mature health systems, patients are encouraged to seek information and share views and decision-making with their doctors. In some democratic states, full participation is ensured in legislation. However, there remains little knowledge of how patients are involved in other contexts.

In this thesis, I focus on China, a new context with a non-publicly funded and developing health system. The Chinese health system is problematic, with poor perceptions of satisfaction and service quality, and the lack of sufficient focus on patient involvement. The Chinese collective approach of decision-making in the family makes it a special case to explore the issue beyond the individual-centred approach in the western context. Moreover, China is not only the country with the largest population and different categories of health insurance, but has a market-oriented health system with a safety net. All these make it an interesting case to explore the meaning of patient involvement and participation in Chinese hospitals. I used interview data from 155 service users of three local hospitals in Shandong Province. I also used policy documents and interview data of other stakeholders, including health professionals, health board managers, academics, an NGO leader and local administrators.

My research findings contribute to the understanding of patient involvement and participation in the Chinese context and how the political, policy, institutional, and individual contexts affect how people wish to be involved in their health care. In terms of political contexts, marketisation and consumerism undermine the trust between doctors and patients. Professionalism, limited political participation and civil society development are all barriers to the promotion of patient involvement in practice. In terms of policy contexts, China lacks policy support for involving patients in health care. The current institutional design only emphasises informed consent at the clinical level. The variation of organisational autonomy and resources and the urban-rural distinction of the population also affect how much people want to be involved. My findings also reveal that age, disease-type, health insurance type, cultural resources, the family influence all affect people's willingness for involvement, although the social capital, seriousness of illness and the stage of condition to some extent are likely to affect their demand for involvement.

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Contents

Abstract	ii
Lay Summary	v
Acknowledgements.....	viii
Contents	xi
List of Figures	xv
List of Tables	xv
List of Abbreviations	xvi
Chapter 1 Introduction	1
1.1 A statement of the problem.....	1
1.2 Research question, purpose, and significance of the study	5
1.3 Structure of the study	7
Chapter 2 Literature Review and Analytical Framework.....	10
2.1 Introduction	10
2.2 Public service delivery — perspective of governance	10
2.2.1 The issue of public service delivery.....	10
2.2.2 From government to governance	11
2.2.3 Health service users as consumers versus citizens	14
2.2.4 Co-production: user participation at the individual level.....	16
2.3 User participation in health care delivery	17
2.3.1 Co-production in health care	17
2.3.2 Patient involvement and participation.....	19
2.3.3 Desire for patient involvement and participation: contexts.....	24
2.4 Practice of patient and public involvement worldwide	31
2.5 The Chinese context	32
2.5.1 Health system in China	33
2.5.2 Chinese health system reforms.....	35
2.6 Research questions and objectives	37
2.7 Concluding remarks	39
Chapter 3 Research Design and Methodology.....	40
3.1 Introduction	40
3.2 Research design	40
3.2.1 Ontology and epistemology.....	40
3.2.2 Research strategy: case study design and qualitative research	41
3.2.3 Methods.....	44

3.3. Data collection.....	46
3.3.1 Data collection procedures for health service users	46
3.3.2 Data collection procedures for other stakeholders	61
3.4 Data analysis.....	63
3.4.1 Data management	63
3.4.2 Abstraction and interpretation	68
3.5 Ethics	68
3.5.1 Confidentiality	69
3.5.2 Informed consent	69
3.6 Reliability and validity	70
3.7 Scope and limitations	70
3.8 Concluding remarks	71
Chapter 4 The Political Context of Patient Involvement and Participation .	73
4.1 Introduction	73
4.2 Neoliberal ideology	73
4.2.1 The worry of costs	74
4.2.2 Inequalities in access to health care	76
4.2.3 Perceptions of marketisation.....	78
4.2.4 Professional-patient relationship	80
4.3 Political system and state-society relations.....	84
4.3.1 Political system	84
4.3.2 State-society relations.....	85
4.4 Consumerism and mechanisms of participation	93
4.4.1 Choices.....	93
4.4.2 Mechanisms of participation: choice, exit or voice.....	98
4.4.3 Consumerism and its problems.....	101
4.5 Summary of findings.....	103
4.6 Concluding remarks	107
Chapter 5 The Policy and Institutional Contexts of Patient Involvement and Participation.....	108
5.1 Introduction	108
5.2 The policy context	108
5.2.1 Health system reforms in China	109
5.2.2 Policy-making and implementation.....	111
5.2.3 Policies of patient rights and empowerment.....	113
5.2.4 Evidence from local administrators	114
5.3 The institutional context.....	116
5.3.1 Promotion of patient involvement in practice	117

5.3.2 Understandings and values of patient involvement and participation	118
5.3.3 Institutional comparisons across cases	133
5.4 Summary of findings.....	137
5.5 Concluding remarks	140
Chapter 6 Taxonomy and Contexts of Involvement and Participation	141
6.1 Introduction	141
6.2 Taxonomy of involvement and participation.....	142
6.2.1 Who are involved in health care decisions?	142
6.2.2 To what extent are you involved?.....	143
6.2.3 To what extent do you wish to be involved?.....	148
6.3 Contexts for desiring involvement.....	152
6.3.1 The individual context	153
6.3.2 The cultural context.....	163
6.3.3 The social context.....	169
6.4 Emergent hypotheses	175
6.5 Testing hypotheses	176
6.5.1 The individual context	177
6.5.2 The cultural context.....	193
6.5.3 The social context.....	197
6.6 Summary of findings.....	204
6.7 Concluding remarks	207
Chapter 7 Discussion.....	209
7.1 Introduction	209
7.2 Macro- and meso-level contexts.....	209
7.2.1 Marketisation and consumerism.....	209
7.2.2 Professionalism	211
7.2.3 The political context	213
7.2.4 The institutional context	214
7.3 Economic and socio-demographic conditions.....	215
7.4 Conflicting values of practitioners: managers and professionals....	217
7.5 Barriers to co-production in health care in China	219
7.6 Concluding remarks	222
Chapter 8 Conclusion	223
8.1 Summary of findings.....	223
8.1.1 The macro-level and meso-level contexts	223
8.1.2 The micro-level context.....	225
8.1.3 Patient involvement and participation in China.....	227

8.1.4 Conflicting values between health managers and professionals	228
8.1.5 The implication for co-production in health care in China	228
8.2 Reflection	229
8.2.1 Generalisability	229
8.2.2 Methods.....	233
8.3 Main contributions	234
8.4 Recommendations for further research	234
References	237
Appendices.....	255
Appendix 1 Interview outline (patients).....	255
Appendix 2 Interview outline (professionals)	260
Appendix 3 Interview outline (health board managers).....	262
Appendix 4 Interview outline (local administers).....	263
Appendix 4.1 Local administers from health authority	263
Appendix 4.2 Local administer from authority of civil affairs	265
Appendix 5 Informed consent (patients)	266
Appendix 6 List of interviews of other stakeholders	268

List of Figures

Figure 1 Multiple-case design (holistic)	43
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List of Tables

Table 1 Interviews by hospital and department	51
Table 2 Interview respondents-Stage 1	51
Table 3 Interviews by disease-type and hospital	52
Table 4 Interviews by age group and hospital	52
Table 5 Interviews by health insurance type and hospital	53
Table 6 Interviews by gender and hospital	53
Table 7 Interviews by hospital and department	54
Table 8 Interview respondents-Stage 2	55
Table 9 Interviews by disease type and hospital	55
Table 10 Interviews by health insurance type and disease-type	56
Table 11 Interviews by age group and hospital	56
Table 12 Interviews by gender and hospital	57
Table 13 Achieved sample of other stakeholders	63
Table 14 Thematic framework	64
Table 15 Example of the framework matrices for theme of cultural capital, social contexts and views of health system	65
Table 16 Comparison of desire for involvement across cases	133

List of Abbreviations

ARS	Abductive Research Strategy
BCT	Breast-conserving Treatment
CC	Cultural Capital
CCP	Chinese Communist Party
CHC	Cultural Health Capital
CHCs	Community Health Councils
CMDA	Chinese Medical Doctor Association
CPPCC	Chinese People's Political Consultative Conference
CSOs	Civil Society Organisations
CYL	Communist Youth League
FTs	Foundation Trusts
GONGOs	Government Organised Non-government Organisations
MI	Myocardia Infarction
MOCA	Ministry of Civil Affairs
MOF	Ministry of Finance
MOH	Ministry of Health
MOHRSS	Ministry of Human Resources and Social Security
NCMS	New Cooperative Medical Scheme
NDRC	National Development and Reform Commission
NGOs	Non-government organisations
NHC	National Health Commission ¹
NHFPC	National Health and Family Planning Commission

¹ The National Health and Family Planning Commission changed its name to the National Health Commission in February 28th 2018.

NMPA	National Medical Products Administration
NPC	National People's Congress
NPM	New Public Management
PA	Public Administration
PPI	Patient and Public Involvement
SARS	Severe Acute Respiratory Syndrome
SC	Social Capital
SDM	Shared Decision-making
UEBMI	Urban Employee Basic Medical Insurance
URBMI	Urban Resident Basic Medical Insurance
RBMI	Residents Basic Medical Insurance
WHO	World Health Organisation

Chapter 1 Introduction

1.1 A statement of the problem

I have never had as many medical interactions with hospitals and health professionals as in the recent five years. I have had opportunities to be informed about health conditions and to make choices of treatments as a patient and as a family member. I remember how I struggled when I had to make a decision with my doctor whether or not I should have a caesarean section a few minutes before I became a mother, and how powerless I felt when I wanted to make a judgement if four stages of chemotherapy were appropriate for my mother, who was diagnosed with breast cancer at an early stage. Even though the principle of 'putting patients at the centre of services' sounds positive and uplifting, not everyone really believes he/she is in the centre of services in the medical encounter. More often, people feel little control over consultations and treatments, as they are frustrated by the negative information and fearful of making decisions. Involving patients in their health care becomes very challenging when it is not certain whether they want to be involved or not.

Nevertheless, the practice of bringing patients back to the centre of health service delivery is a step forward that is worth celebrating for improving service satisfaction and quality. Increased patient involvement in their own health care is of great value due to the improvement in health outcomes and the reduction of costs and risks as 'a potential form of leverage by management' (Coulter and Fitzpatrick, 2000, p. 458). A group of studies regard patient involvement and participation as an instrument to resist medical paternalism and improve autonomy in health care (Coulter, 2005, 2003; Fredriksson and Tritter, 2017).

In a broader sense, patient involvement and participation are seen as a sub-category of public involvement and participation, especially in advanced Western democracies, such as the United Kingdom, Canada and the Netherlands. Practices of Patient and Public involvement (PPI) in health care value the contributions of lay views and knowledge in the service design and

delivery process; i.e. how public resources are distributed and how services are delivered. Examples of citizen or public involvement more generally include patient forums, participatory budgeting and citizen juries (Florin and Dixon, 2004; Hogg, 2009; Rowe and Shepherd, 2002; Sintomer et al., 2008; Thompson, 2020). Correspondingly, a second large group of studies, emphasising the importance of citizen participation and responsibility, believes that public (or citizen) involvement offers a good opportunity to develop a democratic relationship between the state and the citizenry; e.g. deliberative democracy and participatory governance (Parkinson, 2003; Fung, 2015; Callaghan and Wistow, 2006; Fredriksson and Tritter, 2017).

Despite various policy documents and working programmes having underpinned the central role of users, the initiatives do not seem to have been easy to implement (Greenhalgh et al., 2011, p. 2). Patient preferences and experience are identified to be 'optional and varies according to the context and probably over time' (Thompson, 2007, p. 1308). On the one hand, patients are wise and rational: they know how to secure a better outcome. As Charles and De Maio remark (1993, p. 884), patients tend to put themselves 'in the best position to place a value on the benefits and costs of living with the potential consequences of various treatments'. On the other hand, patient views are unstable and emotional. 'Patient expertise tends to be context and temporally specific' (Fredriksson and Tritter, 2017, p. 100) and they may regret their decision-making over time (Thompson, 2007, p. 1307). Moreover, the variation in patient competency in involvement increases the difficulty of implementing shared decision-making (Coulter and Fitzpatrick, 2000, p.459). 'The complexity, multi-faceted and dynamic concept' requires more sophisticated explorations and analyses (Thompson, 2007, p. 1308). The 'contexts', referring to the positions or circumstances patients occupy, are crucial for understanding the meaning of patient involvement and participation at the level of service delivery. Although earlier studies have identified some determining factors of patients' desire for involvement at the clinical level, both through quantitative and qualitative approaches (Buetow, 1998; Coulter and Ellins, 2007; Guadagnoli and Ward, 1998; Rosén et al., 2001; Strull et al., 1984; Sutherland et al., 1989; Thompson, 2007), this issue requires more attention and an in-depth exploration that considers the individual attributes, cultural and social

contexts.

Furthermore, the meaning of patient involvement and participation has been rarely discussed within wider contexts. Most discussions encompass it within a particular context. For instance, in the market-based context, the concept of 'consumers' is widely used to stimulate more rights of choice and exit (Jost, 2007; 6, 2003); in the publicly-funded health system, 'citizens' are used to promote the rights of voice and collective responsibilities in service delivery (Barnes, 1999; Hogg, 2009). However, as Thompson (2020, p. 49) indicates, it is important to consider the macro-level contexts when understanding 'the motivations, forms, processes and impacts of co-production'. As a matter of fact, the governance, funding, organisation and delivery of health services play significant roles in affecting users' identity and the micro-level interactions of health care. These macro- and meso-level contexts, such as the political, policy and institutional contexts, considerably affect how users wish to be involved in their health care. Yet, our existing knowledge and understanding regarding this issue remain relatively under-developed. This study intends to fill this gap through its direct linkage of the meaning of patient involvement and participation to broader 'contexts'. These contexts not only include economic and socio-demographic characteristics of service users, but also a range of macro- and meso-level contexts, such as political, policy, institutional contexts.

Existing academic research provides us with detailed knowledge of patient involvement and participation in many publicly-funded health systems, such as the UK, Sweden and Australia (Hogg, 2009; Rosenberg and Hillborg, 2016; Lopes et al., 2015). But our knowledge of other types of health systems, such as social insurance systems and market-based systems, is rather limited. It is worth noting that my intention in addressing this issue is not to provide a justification of what kind of health system is suitable for patient involvement and participation, but rather to open up a discussion with a few questions: What does patient involvement and participation mean in a non-publicly funded health system? What forms of involvement and participation do service users take? How much do patients wish to be involved in their health care within other contexts?

Given the epidemiological transition from acute disease to chronic disease and the demographic change of ageing populations (Haarmann, 2018, pp. 5–6), health systems internationally are confronted with cost containment, the limited health resources and the increasing demands of services (Entwistle et al., 2018, p. 49). Policy-makers worldwide confront the challenges of balancing the rising demands and cost reduction. In this regard, patient involvement and participation may possibly offer a lever to reduce costs by improving self-management of user groups. It also demonstrates a useful means to reduce harm and promote safety in health care (Coulter, 2011, p. 6). More importantly, involvement and participation offer a good opportunity to involve user voices in health service planning and delivery, enhancing trust in public institutions and democratisation of health service systems (Fredriksson and Tritter, 2017, p. 96). Thus, more research evidence regarding the interplay between contexts and involvement need to be explored, by bringing the perspectives of patients to the health care setting, informing policy-makers of the extent to which users wish to be involved in their health care and what is applicable in practice.

This doctorate study focuses on an underexplored case, namely China. There are three reasons why China is a good choice for studying patient involvement and participation. Firstly, the Chinese healthcare system is still full of unresolved problems, such as poor quality, low satisfaction and resource waste, although a range of policy initiatives have been taken to improve the accessibility and affordability of health services (Li and Krumholz, 2019; Süssmuth-Dyckerhoff and Then, 2017). Substantial gaps in quality improvement and the lack of effective improvement strategies remain in Chinese hospitals (Li and Krumholz, 2019, p. 955). The China National Health Attitudes Survey, which was conducted as a national representative survey between 2012 and 2013, indicates that the Chinese health system is problematic and suggests that more policy interventions should be made to improve the satisfaction and quality of health services (see Munro and Duckett, 2016, pp. 656-657). One of the reasons for the poor performance might be the insufficient focus on patient involvement and participation, which may possibly result in poor perceptions of service satisfaction and quality.

Secondly, the importance of Chinese familism in the area of medical ethics, that is the authority of the family in medical decision-making, makes China a typical case to study non-Western contexts in patient involvement and participation (Bian, 2015). The Confucius collectivism embedded in the Chinese context explains why family members could be important advocates on behalf of patients in medical encounters and how different the collective-orientated decision-making is from the individual-orientated decision-making in the western contexts (Cherry and Fan, 2015). Thirdly, as the biggest developing country with the largest population in the world, China offers an important case for developing our knowledge of patient involvement and participation in a non-publicly funded health system due to its complexity, including not only a huge size of population, but also a large geographic scale and the differences of health insurance coverage among various social groups (Süssmuth-Dyckerhoff and Then, 2017, p. 148). Unlike many mature health systems in the developed countries, China is going through a period of health system transition. China has been making efforts to improve health services in recent decades, after a long-term marketisation of health system reforms in the 1980s and 1990s (Ramesh et al., 2015, pp. 346–349). But overall, China's health system constitutes a system with a pro-market approach, despite the expansion of a universal insurance coverage for the Chinese population (Burns and Huang, 2017, p. 64; Yip and Hsiao, 2015, p. 53). The uniqueness of the macro-level contexts in China, contrasting with many other health systems, motivates our scholarly curiosity to explore the wider social and political contexts that are likely to affect patient involvement and participation and to emphasise that these contexts matter.

1.2 Research question, purpose, and significance of the study

On the basis of the research gaps outlined above, the thesis seeks to answer the following research question:

What does patient involvement and participation mean in Chinese hospitals?

There are three main purposes of the study. First, it seeks to understand the political, policy and institutional contexts of patient involvement and participation in China, including looking at how the political context affects

how patients wish to be involved in their health care, and to what extent policies and institutional design support the practice. Secondly, it aims to investigate the current state of play regarding patient involvement and participation in China, including the taxonomy of involvement and participation in health care delivery, the individual, cultural and social contexts in which service users are positioned and the impact on their willingness for involvement. Thirdly, it addresses the theoretical debates around whether or not co-production of health care in the Chinese context is possible through the interplay of various contextual factors.

The thesis uses an abductive approach as the logic of social inquiry, which enables a better understanding of patient involvement and participation in the new context. It adopts a multiple-case design with three Chinese local hospitals in Shandong Province. I conducted two stages of fieldwork for data collection. At the first stage of fieldwork, I used individual interviews and documents to understand contexts, concepts and theories of the research topic. At the second stage of fieldwork, I conducted interviews to test and refine theories generated in the first stage. I completed 155 patient interviews and 19 interviews of other stakeholders between 2015 and 2019. I used the framework approach and thematic analysis for data management and analysis supported by Nvivo 11.

The study seeks to contribute to the knowledge base of social studies of health care by exploring patient involvement and participation in China. The scarcity of information regarding patient involvement and participation in this new context requires systematic and comprehensive analysis of the meaning of patient involvement and participation. The lack of evidence in the previous studies leaves a large space for exploring and developing a taxonomy of patient involvement and participation and the contextualised factors that are likely to affect the willingness of service users in health care delivery empirically.

Theoretically, this study intends to provide an in-depth analysis of the taxonomy of patient involvement and participation, the contexts at the macro-, meso- and micro-level and their impact on how users wish to be involved in

their health care. The barriers to involving patients in their health care through the lens of various stakeholders, addressed in the study, provides strong evidence for challenging the conventional approach of patient involvement and participation, which might be of interest to policy-makers and frontline practitioners. Methodologically, it seeks to apply the Abductive Research Strategy (ARS) to the exploration of contexts, based on two stages of fieldwork. This approach contributes to the literature on social research by introducing the practice of ARS in the political and policy fields to understand the unknown and new context. Thus, this original piece of work provides an analytical framework and a methodological approach for the research communities to explore the perspectives of patients regarding their health care.

1.3 Structure of the study

This thesis includes eight chapters, of which this introduction is the first. Chapter 2 and 3 provide the theoretical and methodological approaches to this thesis. Chapter 4, 5 and 6 engage with the empirical evidence derived from the analysis of patient interviews and the interviews of other stakeholders in China. Chapter 7 integrates the qualitative data in the previous three chapters to provide an in-depth discussion of the empirical results. Finally, Chapter 8 is the summary of the key findings, the reflection of generalisability and methods, the main contributions and the recommendations for the future research.

Chapter 2 outlines the basic foundations of the study, including a literature review of the theories of governance, citizenship and co-production. It then offers an analytical framework for the analysis of contexts of involvement and participation in health care. It also situates the issue in the Chinese context, by outlining the current health system and health system reforms. It then presents the research questions and objectives on the bases of the theoretical background and the analytical framework.

Chapter 3 details the research design and methodology. It gives the core rationale for the research design, concentrating on the application of ARS and the case study design. It then outlines the qualitative methods and

elaborates on the procedure of data collection, such as the sampling strategies, fieldwork and ethical issues. It also explains the procedure of data management and analysis. It concludes by discussing the scope and limitations methodologically.

Chapter 4 focuses on the analysis of the political context in China. It begins with the analysis of neoliberal ideology in the Chinese health system reforms and the impact on how services perceive the marketisation and the professional-patient relationship. It then explains how the Chinese political system and the relationship of the state and the society affect the practice of patient involvement and participation. It also argues that the approach of consumerism has a significant impact on how service users involve themselves in their health care.

Chapter 5 engages with the analysis of the policy and institutional contexts. It first explores three aspects of the policy context based on the existing literature, policy documents and empirical data. It then examines the institutional contexts that are likely to affect the practice of patient involvement and participation. It allows for a comparison of evidence among three selected local hospitals and argues that the institutional context plays a key role in shaping the values and the practice of patient involvement in health care delivery.

Chapter 6 provides the analysis of empirical data from patients and family carers. It firstly identifies the taxonomy of actual involvement and desired levels of involvement. It then explores the individual, cultural and social contexts of involvement and participation, and develops tentative hypotheses that are likely to affect people's willingness for involvement in their health care. It further tests the hypotheses based on the empirical data in the second stage of fieldwork. It then discusses the results of the empirical analysis and concludes by highlighting the determining factors of the willingness for involvement.

Chapter 7 provides a discussion of the study based on the previous empirical chapters. It focuses on the account of how the contextualised factors at the macro-, meso- and micro-level affect the willingness of user involvement in health care delivery. It also discusses how and why contrasting views of

managers and professionals exist. It lastly explains what hinders patient involvement and participation in China.

Chapter 8 summarises the key findings of the thesis. It discusses the generalisability of the findings and the qualitative methods for data collection. It presents the main contributions and potential directions for future research.

Chapter 2 Literature Review and Analytical Framework

2.1 Introduction

This chapter provides an overview of the different theories of public service delivery and how the theories explain the relationship between public service providers and service users. It then offers an alternative approach to denote the new type of provider-user relationship by introducing the theories of co-production and user participation. It further elaborates theories in relation to patient involvement and participation and reviews some issues that have not been discussed fully in the scholarship.

The study is going to provide an analytical framework to answer to what extent and how patient involvement and participation is desirable and achievable, by analysing contexts that are likely to affect people's willingness to be involved in their health care. I unfold the contexts with six dimensions: the political context, the policy and institutional contexts, the individual context, the cultural context and the social context. These contexts illustrate the conditions for involving service users at various levels in the design and delivery of health services. Then I situate the issue in China and describe the current health system and health system reforms. This chapter presents the theoretical background to the research question: What does patient involvement and participation mean in Chinese hospitals?

2.2 Public service delivery — perspective of governance

2.2.1 The issue of public service delivery

Paul Pierson (2000, p. 257) argues, 'the fundamental feature of politics is its preoccupation with the provision of public goods'. The nature of public goods, including 'lumpiness' and 'nonexcludability', determines how political systems function, especially how public administration works (Lane, 2011, p.2). Today, 'public services', rather than 'public goods', have been buzz words in the theory and practice of public administration and management. As Osborne et al.(2013, p. 136) remarks, most of 'public goods' are 'public services', such as health and social services, and education, and 'they are intangible, process driven and based on a promise of what is to be delivered'.

In theory and practice, the main focus is how to deliver public services. Two paradigms have been debated for decades in public administration and management: Public Administration (PA) was dominant 'from the late nineteenth century through to the late 1970s/early 1980s' (Osborne, 2010, p. 1), with bureaucracy and professionals playing central roles in delivering public services (Hood, 1991); the New Public Management (NPM) has been advocated from late 1970s onwards, putting emphasis on private-sector management techniques and the use of markets, competition, partnership, and decentralisation in public service delivery (Osborne, 1993). However, both of the paradigms have been subjected to criticisms. For instance, the old PA approach has been questioned in relation to the inefficiency and ineffectiveness of policy implementation and public service delivery, while the NPM approach has seen a disappointment for 'its *intraorganisational focus* in an increasingly plural world' and 'the application of outdated private-sector techniques to public policy implementation and public services delivery' (Osborne, 2010, p. 4).

In essence, traditional PA theories insist that the central role of public organisations in public service delivery is bureaucracies, which provide public services by orders, rules and hierarchies. However, the NPM theories assert the roles of private and third sectors, by introducing public-private partnership, contracting, government purchasing and delegating. As a matter of fact, the NPM movements create many innovations in public administration and management practices. The issue of public service delivery becomes more complex within various sectors. These arrangements between public, private and voluntary sectors are framed in the theories of governance.

2.2.2 From government to governance

In recent decades, theories of governance have become one of the main areas of debate in political and social sciences. The term 'governance' has echoed the complexity of political and social issues, bridging many concepts in these fields. The increasing complexity of political and social issues has increased the demand for the involvement of various stakeholders. These stakeholders can be broken down into three categories: governments (the public sector), the private sector and the citizenry. The emergence of

governance theory attempts to bring stakeholders with various resources together and resolve problems in a collective approach (Peters and Pierre, 1998). Stoker (1998, p. 19) points out that 'governance refers to a complex set of institutions and actors that are drawn from but also beyond government'.

However, consensus has not been achieved as to what governance is. Some studies conceptualise it as a process of governing. For example, steering and coordination are suggested to enhance the capacity of governments to meet the challenge of complexity (Pierre and Peters, 2020, p. 13). Other studies give the notion of governance as a structure, which defines 'systems of rule' to replace the role of government (Rosenau, 1995, p. 13), such as 'networks, markets and private standards' (Levi-Faur, 2011, p. 9). Some study also sees governance as mechanisms of decision-making, including 'monetised exchange, non-monetised exchange, command, persuasion and solidarity' (Levi-Faur, 2012, p. 10). Fundamentally, the concept of governance is related to power: who governs and how to govern. Incorporating the instruments of decision-making and resource allocation, the theories of governance attempt to provide a normative framework for how to exercise power and make use of resources in terms of 'knowledge', 'organisations' and 'authority' (Papadopoulos and Benz, 2006, p. 2).

In the last few decades, a consensus has emerged around a shift from 'government' to 'governance'. The meaning of governance refers to 'a *new* process of governing; or a *changed* condition of ordered rule; or the *new* method by which society is governed' (Rhodes, 1996, pp. 652–653). The shift from 'government' to 'governance' is summarised in three directions: 'upward (to the regional, transnational, intergovernmental, and global), downward (to the local, regional, and the metropolitan), and horizontally (to private and civil spheres of authority)' (Levi-Faur, 2012, p. 8). Therefore, governance is not considered as the same with government. Rather, it is seen as 'more than government, or an alternative to government' (ibid., p. 11).

There are a variety of patterns and modes of governance in theory. Basically, three approaches of governance have been discussed in the scholarship. The first approach is the state-centred approach, which highlights the leading role for the state in the governance process. For example, Peters and Pierre

(2016, p. 1) emphasise the competence and capacity of the state to control and regulate at the centre of governance, instead of being distancing from the state. Matthews (2012, p.292) also suggests that the active reconstruction of state capacity helps to deal with the increasing complexity and interdependencies in policy and political fields. Levi-Faur (2012, p. 13) supports the multi-level autonomy of the state with the evidence of the EU regulatory regimes, rather than interdependence with the market and society. Papadopoulos and Benz (2006, p. 4) highlight the institutional design of the state, which makes it necessary to 'define who is authorized to act and to make collective binding decisions'.

There also emerges the political-social approach that asserts the interplay of political and social actors. For example, Rhodes (1994, p. 138) uses 'hollowing out of the state' to describe that the central and local governments in Britain were losing functions to other agencies and to the EU, with new forms of service delivery systems in the 1980s and 1990s. He points out that 'self-organising interorganisational networks' have been an effective approach of governance to fill up markets and hierarchies for allocating, controlling and coordinating power and resources (Rhodes, 1996, p. 652). Again, Kooiman (2003, p. 96-114) proposes 'co-governance' with various forms, such as public-private partnership, communication, co-management, networks, regimes and synthesis, which highlights the interactions and arrangements among various actors in the reality of governance.

However, both the state-centred approach and the political-social approach are mostly discussed in the context of neoliberal reforms of the public sector and as 'a shift in public organisations and public action from hierarchic bureaucracies to markets and networks' (Bevir, 2013, p. 9). These policy reforms are mainly focusing on the improvement of efficiency through governance (Ron, 2012, p. 475). Yet, there is a new approach of citizen-centric governance in the forms of democratic governance and participatory governance that emphasise citizen participation, the democratisation of political systems and the structural changes for non-democratic authorities (Fischer, 2012, 2006; Fung, 2015; Pateman, 2012). The literature of democratic governance not only concentrates on the participatory mechanisms in the developed democracies (Wagenaar, 2007), but also expands the discussion to the non-democratic political systems (Weltbank,

1997). The citizen-centric approach advocates the creation of space for institutionalised civil society organisations and non-institutionalised citizens in policy-making and service delivery (Cornwall and Shankland, 2008; Phillips, 2012). Unlike the conventional approach of service delivery treating citizens as passive recipients, it is well recognised that active citizen participation in the process of governance is beneficial to tackle public problems (Fischer, 2006, p. 19) and to provide new approaches of public service delivery. New participatory mechanisms in practice are developed to engage with citizens, such as citizen assemblies, participatory budgeting and deliberative polls (Fung, 2015; Fung et al., 2003). The next section is going to elaborate the relationship between service providers and citizens from the perspective of citizenship.

2.2.3 Health service users as consumers versus citizens

While theories of governance offer a new link between public service providers and service users, the framework of citizenship conceptualises the relationship between these two sides. Social citizenship, which is developed by Marshall (1963) in the context of a modern welfare state, defines social rights as an important dimension of social benefits beyond the scope of civil rights and political rights. But Marshall's citizenship fails to address 'many of the complexities of diverse, modern societies in a globalized environment' (Phillips, 2012, p.487). The active citizenship is increasingly evoked, including civil virtues, responsibilities and loyalties (Kymlicka and Norman, 1994). The theory of citizenship also promotes the sense of belonging to the political community through active citizen engagement (Phillips, 2012, p. 487-488).

Correspondingly, in the field of public services, service users are given sufficient attention in the design and delivery of public service. According to Fotaki (2011, p. 937), the importance of users is that they are 'the stakeholders partaking in the creation of a public good'. Citizenship in public services is thus conceptualised in two forms: users as consumers and as citizens. Influenced by the ideology of neoliberalism, which introduces contracts, competition and public-private partnerships, the market approach encourages consumers as private individuals to exercise rights of choice and exit based on the control of information and resources (Fotaki, 2011, p. 945).

It is assumed that users as consumers are those 'who is informed and knows what they want, and is able to judge the quality of what they receive' (Greener, 2008, p. 100). Consumerist choice is central in the policy discourse of marketised reforms and is believed to be an instrument for achieving various policy goals, including efficiency, quality, responsiveness and equity (Fotaki, 2013, pp. 121–122). But competition and consumerist choice have seen a failure in practice, such as the serious asymmetry of information that exists between service providers and users in many specific areas; e.g. health care (Jost, 2007, p. 86-118). There also emerges the increasing problem of inequality for particular groups who have no power and control over information, choices and exit; e.g. the elderly, the disabled, the less educated and the poor (Jung, 2010, pp. 442–443). Choice itself is also criticised to be meaningless when geography constrains choices of service users (Greener, 2008, p. 96).

The other form of users as citizens rejects the consumerism approach due to its incompatibility with the nature of public services (Jung, 2010, p. 441) and supports the collective approach of user empowerment and community involvement (Barnes, 1999). Users are given the identity of 'citizens', who are able to use voice and participation to exert political influence in a collective way. Collective action, including user self-organisations and social movements, is distinguished from consumerism, which seeks to realise the maximisation of individual self-interest (*ibid.*, p. 82). These practices spread across the fields of health and social care, urban regeneration and community planning at the state and local levels (Barnes et al., 2003; Lowndes et al., 2001a, 2001b; Simmons and Birchall, 2005).

Nevertheless, both marketised and collective approaches reject the traditional provider-centric model and recast the role of service users in policy design and service delivery. While consumer participation tends to promote the use of individual choice to express needs, wants and (dis)satisfactions, citizen participation, on the other hand, seeks to change the relationship between providers and users with voice and political influence. The citizenship of participation gives theoretical foundations to involve citizens in the design and delivery of public services in practice. Another dimension concentrating on the citizenship of participation in service delivery is also worth noticing. In the next section, I review the development of user

participation at the individual level.

2.2.4 Co-production: user participation at the individual level

As user participation has been greatly valued in the last few decades, the concept of 'co-production' in public service delivery is denoted as the new type of provider-user relationship. Originating from the USA in the late 1970s and the early 1980s (Brudney and England, 1983; Ostrom, 1972; Parks et al., 1981; Whitaker, 1980), the term was then introduced to Europe and Australasia (Alford, 2002; Bovaird, 2007) and some developing countries (Ostrom, 1996). Although 'co-production' is a buzzword, the initial research does not achieve a consensus regarding several issues. First, there is a conceptual confusion of who co-producers are. Some define 'coproducer' as 'organised groups of citizens' (Joshi and Moore, 2004, p. 40), some divide individual users and community groups (Bovaird, 2007, p. 847), others exclude volunteering from co-production (Alford, 2002, p. 34). Second, the classification of co-production remains unclear. Some only refer to individual co-production between service providers and users (Ostrom, 1996, p. 1073), some extend the scope to group co-production and collective co-production (Brudney and England, 1983, pp. 63–64). Nevertheless, the idea of co-production was promoted in the 1980s and 1990s due to the overuse of market-oriented means in the New Public Management and relevant reforms (Nabatchi et al., 2017, p. 767).

In recent decades, there has been an increase in systematic publications of co-production in theory and empirically. Some have discussed the debates over conceptual confusions, the scope of application and the typology of co-production (Alford, 2014; Brandsen and Honingh, 2016; Nabatchi et al., 2017; Osborne et al., 2016; Pestoff et al., 2013). Alford (2014, p. 304) clarifies that 'although the idea of consumers also being producers might attract our attention, it is not the only form that co-production can take. It often involves more than a simple two-person interaction, and groups as well as individuals.' Brandsen and Honingh (2016, p. 431) also redefine co-production as 'a relationship between a paid employee of an organisation and (groups of) individual citizens that requires a direct and active contribution from these citizens to the work of the organisation'. In other words, co-production specifically refers to the contribution of (groups of) individual service users in

the service delivery process. Pestoff et al., (2013, pp. 18-19) distinguishes co-production from co-management and co-governance, referring to 'an arrangement where citizens produce their own services'. Again, Osborne et al. (2016, p. 645) develop a typology that distinguishes co-production from co-design, co-construction and co-innovation in the context of public service delivery. Meanwhile, some literature is dedicated to providing more robust empirical evidence of co-production in many fields, such as health care (Batalden et al., 2016; Thompson, 2020), social care (Jaspers and Steen, 2018) and education (Lindsay et al., 2018). Co-production is embraced by policy-makers and practitioners, as it is believed to open up an opportunity for cost reduction (Durose and Richardson, 2016, p. 36), the increase of effectiveness (Osborne et al., 2013, pp. 148–149), quality and satisfaction of services (Batalden et al., 2016, pp. 509–513).

2.3 User participation in health care delivery

Given the values of co-production in public service delivery, I elaborate how it works and does not work in the context of health care delivery in the Chinese context. Health care is used as a case to illustrate user participation and to inform our understanding of the processes and perceptions of delivery in theory and practice. The following sections provide a comprehensive literature review on various aspects of co-production.

2.3.1 Co-production in health care

Batalden et al. (2016, p. 515) remark that 'this lens of coproduction will help us see healthcare service with new eyes'. In recent decades, scholars and practitioners have paid a wealth of attention to co-production in health care due to the unique features of public services with an intangible process, the simultaneity of production and consumption and the compulsory roles of users as co-producers (Osborne et al., 2013, p. 139). Many studies underline the role of users (i.e. patients and carers) as partners in co-producing health care, including theoretical debates and discourse in different health systems (Batalden et al., 2016; Dunston et al., 2009; Eriksson, 2018; Ewert and Evers, 2014) and empirical evidence at various levels of practice (Greenhalgh et al., 2011; Jo and Nabatchi, 2018; Rosenberg and Hillborg, 2016; Sabadosa and

Batalden, 2014). A key driver for promoting co-production is the demand for quality improvement in the delivery of health services (Butler & Greenhalgh, 2011, p. 14). The other driver is the increased emphasis on lay knowledge in its contribution to health care (Prior, 2003) and democratisation of the professional-patient relationship (Hunter, 2004, p. 52).

However, co-production in health care has proven difficult for the implementation in practice. One of the biggest obstacles is the power imbalance between health professionals and patients. Previous studies demonstrate the gap of knowledge and the power relationship. Freidson (1970a, p. 5) illustrates that a professional in medicine means 'not merely that of prestige but also that of expert authority'. The term 'professional' essentially refers to a particular occupation with the possession of formally-trained knowledge. On the contrary, the term 'patient' has passive meanings of deference, behaving patiently with fewer resources and little control over the clinical encounter (Lawrence, 2008, p. 21). According to Freidson (1970b, pp. 210–213), the occupation of the professional is able to obtain institutional power that takes away patient rights and decision-making power of patients. This means that the nature of the relationship is unequal, as medical professionals are dominant and authoritative. In the context of health facilities, patients tend to give up their rights, as their main concerns are individual health.

'The right-duty concept affects at least three specific areas of decisions concerning the health care of the individual: the right to the whole truth, including information that is part of medical records both during and after treatment; the right to privacy and personal dignity; the right to retain self-determination...More problems can be diagnosed and treated, the doctor's time is more in demand, and he has less time to spend with his patient to develop a working relationship of trust and mutual respect.' (Annas and Healey, 1974, pp. 248-252)

Although there are obstacles to user participation and empowerment, the idea has received persistent attention within various scholarly disciplines, including sociology, political sciences, management studies, bioethics. New research sheds valuable insights to the changing models of the professional-patient relationship, from professional-dominant to patient-centred (Charles

et al., 1997; Coulter, 2003; Entwistle et al., 2014; Entwistle and Watt, 2006). There has also been a surge in newly emerging concepts, including patient involvement and participation (Angel and Frederiksen, 2015; Cribb et al., 2011; Entwistle et al., 2008; Fredriksson and Tritter, 2017; Greenhalgh et al., 2011; Thompson, 2007), patient-centredness (Langberg et al., 2019; Mead and Bower, 2000; Stewart, 2003), and patient empowerment (Agner and Braun, 2018; Pekonen et al., 2019; Yeh et al., 2018), which are corresponding to the increasing rights and influence of patients and carers in their encounters with health professionals. These concepts are given different meanings from various perspectives. For example, the approach of patient-centredness develops a more comprehensive system of the doctor-patient relationship (Mead and Bower, 2000). Patient involvement and participation is more concentrated on the actual behaviours of information seeking and shared decision-making (Thompson, 2007, p. 1302). Empowerment is another dimension of patient-centred care, which is related to patients' motivations and competencies to control and manage their health and health care (Fumagalli et al., 2015, p. 390; Pekonen et al., 2019, p. 2).

Nevertheless, these concepts provide a linkage to co-production in health care and enrich our understanding of user participation in health service provision. In this research, the term 'patient involvement and participation' is more frequently used to denote user participation in health care delivery. This is due to two key reasons: patients are at the centre of the study, although it involves carers in particular circumstances; the majority of studies in patient involvement and participation is more related to the fields of politics and health policy. In the next section, I review the literature on patient involvement and participation.

2.3.2 Patient involvement and participation

The first question is to make a distinction between involvement and participation. In the English language, there are obvious differences between involvement and participation: the former has a wider scope but with passive meanings, while the latter has more active meanings. In the health arena, Thompson (2007, p. 1299) distinguishes participation from involvement: participation is an ideal form of relationship with the engagement of two-way communication and shared power on the basis of mutual respect and

openness. Entwistle and Watt (2006) expand the concept of patient involvement to various aspects of decision-making, including their views and preferences and their contributions in relation to professional-patient relationship, decision-making and health care outcomes. Accordingly, patient involvement is a more common situation at the clinical level than patient participation, as it includes lower levels of participation.

More often, patient involvement and participation is regarded as one dimension of PPI, which is stressed by a range of literature on a multi-level design of user involvement in the design and delivery of health services (Brett et al., 2014; Cartwright et al., 2011; Farrell, 2004; Mockford et al., 2012; Tritter, 2009). A notable work of making the distinction between patients and the public suggests that they have 'different roles, perspectives, experiences, expectations and interests' (Fredriksson and Tritter, 2017, p. 107).

The second issue is related to why involvement is embraced. First, significant changes in health care system have emerged in western countries. Haarmann (2018, pp. 5–6) concludes four substantial changes of health care and health systems over the last decades: demographic change that results in a higher utilisation of health services; epidemiological transition from acute disease to chronic disease; new technologies that promote the emergence of treatment options; policy reforms of health service funding, provision and quality. These changes have been reflected in the changed roles of patients and the professional-patient relationship: new roles of patients are defined by some as 'customers', 'consumers' and 'service users', empowering more individual rights such as choices and shared decision-making (Haarmann, 2018, p. 6). Meanwhile, organisational inabilities have resulted in problems with health service provision, such as 'high mortality rates or significant patterns of complaints from service users', which call for new ideas in managing health services (Cartwright et al., 2011, p. 16).

The third issue is concerned with the benefits that patient and public involvement have. Most literatures highly appraise the value of patient and public involvement, including intrinsic and instrumental benefits. Instrumental benefits are evidenced in the previous studies, such as the improvement of health literacy, clinical decision-making, self-care and patient safety (Coulter, 2011; Coulter and Ellins, 2007), service quality management (Armstrong et

al., 2013; Bovaird, 2007; Haxby et al., 2010) and better service satisfaction (Entwistle et al., 2014). Intrinsic value at the individual level mainly refers to the right to self-determination (Guadagnoli and Ward, 1998, p. 337). Whereas the evidence of positive impacts is found at the individual level, there are not fewer literature of the impact of group and collective involvement on health care delivery. Rosenberg and Hillborg (2016) evaluate collective user influence with the case of user advisory boards in substance abuse and mental health services in Sweden. However, more robust evidence regarding the impacts of patient and public involvement on health services are needed.

The context of this study is patient involvement and participation at the micro-level of service delivery. In the following sections, I am going to review the literature of patient involvement in two aspects: information-seeking and decision-making.

2.3.2.1 Information-seeking

Information is seen as one of the most crucial components in health policies, which is emphasised by the importance of information provision in some health system reforms. For instance, the Department of Health in England proposed and implemented information at the centre of health care in the early 2000s, including 'Patient Information Bank', NHS Direct Interactive, Health Direct and 'Information Prescriptions' (see Cayton, 2004, pp. 10-13). Further, the provision of good quality information is at the core of service delivery processes, such as informed consent, self-care and patient choice (ibid., p. 3). As choice becomes one of the key reforms in the health care system, information has been a pre-requisite for making choices and informed decisions. A growing body of literature highlights the value of information for patients and their families and carers, as it ensures people receive the right information at the right time and make better choices (Blanchard et al., 1988; Cayton, 2004; Coulter, 2003; Coulter et al., 1999; Gaston and Mitchell, 2005). Meanwhile, some studies confirm that information is beneficial to reduce health inequalities and to overcome barriers of health service delivery (Cayton, 2004, p. 5).

Two types of information are documented in the literature: general facts

(known as optional/outcomes information) that help offer scientific or research-based information about potential options and possible outcomes (Coulter et al., 1999, p. 318; Wyke et al., 2011, pp. 111–112); personal experience information, which refers to ‘accounts of personal experience’ of illness and health care processes (Entwistle et al., 2011; France et al., 2011; Winterbottom et al., 2008, p. 2080; Wyke et al., 2011, p. 15). Information is also demonstrated in various formats, such as the consultation of health professionals, the internet, printed/written materials, family members, relatives and friends (Jo et al., 2019). Some studies also demonstrate how people use and value information of various types and sources, and how it informs individual decision-making (Khangura et al., 2008; Sillence et al., 2007; Winterbottom et al., 2008). Currently, the variation in uses and preferences of information by age, gender, socio-economic status, and chronic/acute conditions means that the associations between demographic and socio-economic factors, and the use and preferences of information remain unclear.

2.3.2.2 Treatment decision-making

The involvement in decision-making is an essential element of patient involvement and participation. Traditional views of patient involvement and participation focus on the appraisal and selection of treatment options (Charles et al., 1997; Strull et al., 1984; Sutherland et al., 1989), but recent work tends to broaden the concept of decision-making to a range of activities, such as ‘recognition and clarification of a problem, identification of potential solutions, appraisal of potential solutions, selection of the course of action, implementation of the chosen course of action and evaluation of the solution adopted’ (Entwistle and Watt, 2006, p. 274). Compared to the earlier work that concentrates on the behaviour of patients, recent literature also pays attention to the perceptions of people’s roles and efforts in the decision-making process (ibid.).

The description of models of patient involvement and participation is drawn from previous theories. Based on Arnstein’s ladder of citizen participation in 1969, a classic model is developed with four types: paternalist model, informed decision-making model, professional-as-agent model and shared decision-making (Charles et al., 1997; Charles and DeMaio, 1993). The

notable work written by Charles and her colleagues also discusses the differences between several models and remarks that shared decision-making offers a middle potential choice of the treatment decision-making model between two polar extremes (Charles et al., 1997, p. 688). With the increasing interests in shared decision-making, some literature points out that the model should be focused on the preferences of patients, as it is beneficial to improve the knowledge of patients and satisfaction with services (Clayman et al., 2017; Coulter, 2005; Pieterse and Finset, 2019). Although the current emphasis is on the preferred roles of physicians (Driever et al., 2019), it receives scant attention as to how patients and carers perceive their roles of shared decision-making. Moreover, a distinction is being made between actual involvement and desired levels of involvement (Thompson et al., 2007, p. 176). Other research also suggests that severe illness, poor health and age are likely to hinder actual involvement although patients might desire a more ideal participation (Angel and Frederiksen, 2015, p. 1530).

2.3.2.3 Mechanisms of involvement and participation

The other important aspect of patient involvement and participation is the mechanism of involvement and participation; i.e. what forms it takes to be involved in health care delivery. Hirschman (1970) conceptualises participation with two mechanisms: exit and voice, which are used by consumers to show their satisfaction (or dissatisfaction) with the quality of products in the context of the United States. Hirschman's model describes 'choice' and 'exit' as economic options to switch from one product to another, while 'voice' is 'a political action par excellence' to require a change of quality or improve the relationships with the providers through communication (ibid., p. 16). However, the framework is more applicable to the healthcare system in the United States in the 1970s when health care was paid by users as consumers. In other contexts, the terms 'choice' and 'exit' are not always equivalent. For example, 'choice' is used interchangeably with 'exit' in welfare states, such as the British National Healthcare System, as there are no other options to exit from the NHS for most people (Haarmann et al., 2010, pp. 215–216; Le Grand, 2003, pp. 9–11). In corporatist health care systems, such as Germany and France, choice and exit not only refer to the changes of hospitals and doctors, but also insurance funds, due to the separation of purchasers and providers (Haarmann et al., 2010, pp. 228–229).

Nevertheless, the economic model has been challenged in the field of health care, in that it undermines health care as a non-market good, individual autonomy and good medical practice (Emanuel and Emanuel, 1997, pp. 165–166). In Hirschman’s model, voice and exit exist in a complementary relationship that voice only works when there is a possibility of exit (Dowding, 2016, p. 259). There are also other views that distinguish voice from choice, advocating it as a new ideological relationship of partnership (Thompson, 1999, 2007). The involvement through voice, whether at the individual or collective levels, is believed to empower users to take control of health care processes, express their dissatisfaction through complaints procedures and contribute to the changes in the healthcare system. This also provides a linkage to the scholarship of citizenship in public services, as reviewed in Section 2.2.3.

2.3.3 Desire for patient involvement and participation: contexts

While there is an increasing attention to the understandings of patient involvement and participation, there is a lack of sufficient evidence with regards to how much they desire involvement and participation from the perspectives of patients and lay carers, such as their spouses, children and siblings. Some earlier studies suggest that patient preferences should be identified and explored in the consultations (Buetow, 1998, pp. 245–246; Guadagnoli and Ward, 1998, p. 337). Notably, Thompson (2007, pp. 1306–1307) develops a taxonomy with five levels of patient-desired involvement, including non-involvement, information seeking/information-receptive, information giving/dialogue, shared decision-making, autonomous decision-making. But it requires further exploration of why patients change their preferences from one context to another and what factors affect their roles and preferences in their health care. There is a need for further research to explore ‘the social and political contexts that give power, morality and meaning to patient involvement’ (Glenister, 1994, p. 808; Thompson, 2007, p. 1308).

In order to understand the meaning of patient involvement and participation, I start by exploring the contexts of patients. In this thesis, I highlight ‘context’ as the foundation of the analysis. ‘Context’ can refer to the situations that

give meanings to involvement and participation. In the health arena, 'context' also describes the 'positions' where patients are, which might affect patients' roles in health care decisions. Drawing upon the previous theories, I will unfold the analysis of contexts that give meanings to patient involvement and participation in health care with six dimensions: political, policy, institutional, individual, cultural and social contexts. This enables a comprehensive understanding of when, to what extent, and how involvement and participation are desirable and achievable, from the perspectives of service users. The analysis of contexts also provides the understanding of the position of service users; i.e. patients and lay carers.

2.3.3.1 The political context

The political context concerns how health is governed. The type of governance determines the substance and form of policies that emerge. It consists of the ideology, the framework and policies that have been made, and the groups who decide what policies. In the thesis, the political context is considered as a key factor that affects the practice of patient involvement and participation. The first element of the political context is ideology in the health sector, which consists of 'a comprehensive set of political beliefs about how the world works and how we should engage with it' (Cairney, 2011, p. 221). Ideology shapes the position of users in the interactions of health care, as it drives policy actions and institutionalisation in health authorities. Two streams of ideology have been documented by scholars in the health sector: the pro-market ideology, which believes that the invisible hand of the market and individual choice are more effective than centralised administration (Yip and Hsiao, 2015, p. 53); the pro-government ideology, on the other hand, values patients as co-producers and partners of health care in practice and seeks to establish a more participatory, democratic and equitable health system (Thompson, 1999). In this regard, Titter (2009, pp. 279–280) implies that the stress of the central role of patients and the public are particularly true in publicly funded health systems, rather than social health insurance or market-based systems.

The second element of the political context is the political system and state-society relations. Freeman (2000, p. 8) underlines the relationship between health care and politics arguing that 'health problems are state problems,

health systems may be understood as being embedded in those political processes of which the state forms a part'. Thus, health policies and problems are closely related to what the political system is; e.g. corporatism, pluralism or totalitarianism, etc. Meanwhile, the relationship between the state and the society is considered as an important variable, as it concerns 'how a society structures its responses to domestic health challenges' (Huang, 2013, p. 5) and how service users involve themselves in the policy-making and service delivery.

2.3.3.2 Policy and institutional contexts

The policy and institutional contexts are connected but demonstrate different levels of influence. Specifically, the policy context at the macro-level provides the instruments policy-makers use for achieving policy strategies. The institutional context at the meso-level refers to the administrations and practitioners within the policy areas of health care. It is relevant to how professionals and bureaucrats interpret policies in their own organisations. In this sense, the policy and institutional contexts interface with each other.

In this thesis, the policy context is considered as a key variable to affect how users wish to be involved in health care delivery. It includes what roles patients are given in health reforms, how health policy-making and implementation are carried out, and what values policy-makers have regarding patient involvement and participation. Many developed countries, mostly European countries with mature health care systems, enact laws and make policies to guarantee the involvement and participation rights of patients and citizens. For example, a series of laws have been enacted to reinforce the central role of patients in the Netherlands, such as the Medical Treatment Agreement Act in 1994, Care and Healthcare Complaints Act in 1995, Quality for Care and Healthcare Units Act in 1996 (see Haarmann, 2018, pp. 89-90). Another example is the Patient Rights (Scotland) Act (2011), which regulates that patients should be encouraged by health professionals to participate fully in decisions that are relevant to their own health, and patients should be provided with information and support to facilitate their involvement in the process of service delivery. However, there remains a lack of evidence regarding how other countries, especially the less developed countries, provide policy support for patient involvement and participation.

Further, the relationship between central and local health systems, illustrating how health policy-making and implementation are carried out, is identified as a significant factor, which concerns who fund, manage and deliver health services, and who have the power to make, implement and evaluate policies. Haarmann (2018) compares the redistribution of power across four health care states and identifies that the Netherlands, England and Sweden decentralise patient involvement and participation at the local level, while Germany centralises involvement at the state level. Again, Jost (2007, p. 170) identifies that regional governments play a major part in operating a health care system in many public funded systems, while the state governments play a key role in operating hospitals and distributing resources in some social insurance systems. In addition, the extent of which patient involvement and participation are promoted and implemented is relevant to how policy-makers value and understand it. For instance, the policy-makers in the UK realise the benefits of user involvement, including achieving better quality and reducing cost (Greenhalgh et al., 2011, p. 14).

The institutional context is another significant variable of how the meso-level context affects how users wish to be involved in health care. Some research discusses that the beliefs of health professionals are likely to affect whether or not and how patient involvement is promoted in practice (Driever et al., 2019). But not many studies concentrate on the investigation of values and attitudes of health managers in the hospitals and health boards. It is more related to the wider context of institutions. The differentiation of health facilities, such as institutional design and the targeted population (i.e. urban and rural settings), plays a key role in promoting or hindering patient involvement and participation. Also, those organisations which value the benefits of patient involvement have different ways of operationalising the idea, such as health or citizen panels, or involvement forums (Tritter, 2009, p. 277). In this regard, the institutional context, despite the interface with the policy context, demonstrates a significant influence as the meso-level variable on the issue.

2.3.3.3 The Individual context

The individual context refers to individual attributes and factors that are likely

to affect people's desire for getting involved in their health care. According to the existing scholarship, three layers of the individual context are identified: individual attributes, attributes of illness and the relationship with professionals. The first layer is individual attributes, such as age, gender, education and socioeconomic status. Some earlier studies reveal that young, female, well-educated and rich patients are more likely to be involved in health care decisions, or have more willingness to be involved (Strull et al., 1984; Sutherland et al., 1989). Rosén et al. (2001) also note that patient preferences are associated with age, based on a survey in Sweden. The second layer is attributes of illness, which are characterised as the type of illness and the seriousness of health conditions. Previous studies show that patients with chronic disease are more willing to be involved in self-care and self-management (Coulter and Ellins, 2007). Thompson (2007, p. 1307) identifies that patients who suffer from severe illness are less likely to be involved in decision-making process due to the lack of expert knowledge and the emotionally weak position. The third layer is the relationship between patients and professionals. Again, in a qualitative study of the UK, Thompson (2007, p. 1307) reveals that the relationship, depicted by the degree of trust, is very likely to affect the dependency on doctors.

2.3.3.4 The cultural context

There has been an increasing attention to the cultural context, which narrowly refers to the 'cultural capital' that one possesses in the health setting, and how he/she uses it in the process of health care delivery. Specifically, the term 'cultural capital' refers to cultural resources, such as educational level, professional expertise in health care, which might facilitate or hinder the involvement and participation.

Bourdieu produces the most prominent work on the conceptualisation of capital. He conceptualises capital in three forms: 'as *economic capital*, which is immediately and directly convertible into money and may be institutionalized in the form of property rights; as *cultural capital*, which is convertible, on certain conditions, into economic capital and may be institutionalized in the form of educational qualifications;...as *social capital*, made up of social obligations ('connections'), ...and may be institutionalized in the form of a title of nobility' (Bourdieu, 2011, p. 82).

In the field of health care, cultural capital receives much attention by scholars, as it is seen as an important place where cultural capital is dominant (Callaghan and Wistow, 2006, p. 587). According to Bourdieu (2011, p. 82), it exists in three distinct forms: in the incorporated state, as forms of values, norms and knowledge; in the objectified state, which is in the form of cultural products, such as books, pictures, dictionaries, instruments; in the institutionalised state, such as educational degrees and vocational qualifications. Correspondingly, some research proposes the notion of cultural health capital (CHC) in the context of health care (Abel, 2008; Shim, 2010). Abel (2008, p. 2) specifically develops the framework of the three dimensions: incorporated state (also known as embodied state), which refers to values, behaviour norms, knowledge and skills that are relevant to health issues; objectivised state, referring to tangible resource such as health books and access to the internet; institutionalised state, which refers to health-relevant certificates, diplomas and qualifications. Dubbin et al. (2013) use the framework of cultural health capital to explore how cultural resource assets and interactional styles influence the capacities of patients and providers in order to achieve patient-centred care.

In this study, 'formal education' measures the incorporated state of cultural health capital; 'access to internet', 'the frequency of mass media relating to health and health care' and 'availability of health books' measure the objectivised state; 'qualifications and certificates of work in health care' measures the institutionalised state.

2.3.3.5 The social context

Researchers also explore the associations between the social context and involvement in health care. The social context has a dominant influence over health behaviours and health disparities (Burke et al., 2009) and 'directly and indirectly affect health and behaviour' (Pasick and Burke, 2008, p. 359). The social context is different from the cultural context. It puts more emphasis on social capital in the health encounters, which is based on durable social networks and connections (Bourdieu, 2011, p. 86-87). Individuals do not have social capital, but they may have access to social capital, as a collective resource. The cultural context, on the contrary, refers to the cultural

resources of individuals that can be utilised in seeking information and making health decisions in this study.

The first layer of the social context is family influence, which has been explored in different health systems. Hilton (1994) conducts family interviews with breast cancer patients and identifies four patterns of family decision-making: 'defer to physician', 'minimal exploration', 'joint engagement' and 'extensive examination'. Hubbard et al. (2010) explore the role of the carer in treatment decision-making, including information exchange and facilitation of deliberation. Laidsaar-Powell et al. (2016) examine a range of factors (patient, family, cultural, relationship and decision) that affect family involvement in Australia. Lee and Knobf (2016, p. 1495) identify that family involvement includes gathering information, accompanying, making decisions, maintaining family life and navigating the healthcare system, based on a qualitative study of Chinese-American women with breast cancer.

In Chinese bioethics, the family provides one of the social contexts for patients being involved in health care delivery. 'Confucianism' unlike the Western individualism, regards the family as a whole 'to make such decisions and as the best authority to make such choices' (Fan, 2007, p. 20). Family members are regarded as the legal party to sign any informed consent in most Chinese biomedical contexts (Fan, 2015, p. 4). This collectivism of medical decision-making, which is popular in the East Asian health care context, sometime excludes patients from the decision-making process, when patients are seen as having vulnerable roles under some circumstances, such as cancer (Menon et al., 2020, p. 31). Although Chinese collectivism is understood as denoting both cultural and social contexts in the literature (Cherry and Fan, 2015; Fan, 2015), I clarify that in this thesis, family is given more stress as a social context of patient involvement and participation, with 'the existence of a network of connections' (Bourdieu, 2011, p. 87). It takes the perspective of patients and their contexts, rather than patients and their family in the context of health care. In this study, I explore how the family as the social context is involved in health care delivery and whether or not patients wish their families to be involved.

The second layer of the social context is social capital. Bourdieu (2011, p. 86) notes that social capital refers to 'the membership in a group'¹¹—which

provides each of its members with the backing of the collectivity-owned capital, a 'credential' which entitles them to credit'. On the other hand, Putnam (2000, p.19) indicates that social capital is embodied in 'the connections among individuals—social networks and the norms of reciprocity and trustworthiness that arise from them.' He also illustrates that social capital has two faces: social networks as an individual good benefits people's own interests; it is acting as a public good to foster mutual obligations and civic virtue in the community (Putnam, 2000, p. 20-21). To distinguish social capital between Bourdieu's and Putnam's concepts, Munro (2012, pp. 153–154) illustrates that Putnam's social capital broadens Bourdieu's definition of the 'credential' by extending trust in an institution, which makes it work more efficiently.

In the field of health care, it gives more attention to the private face of social capital; i.e. the social networks and resources, of which patients and their families can make use to benefit their health and health care. It enables us to examine how social capital makes a difference among various groups in terms of the willingness for involvement and participation. In this study, I consider 'extra help from the health system' and 'patient networks' as measurements to examine how much social capital a patient access to beyond formal health service provision.

2.4 Practice of patient and public involvement worldwide

The practice of patient involvement and participation is widely promoted in the delivery of health services. A number of initiatives have been taken to improve service quality and patient safety in many fields, such as cancer, diabetes and mental health. For instance, patients are invited in groups by service providers to reduce diagnostic errors during the process of diagnosis (Jo and Nabatchi, 2018). Another example is the Leap for Patient Safety in the United States, where media stories are collected in the website to illustrate how medical malpractices and errors take place in the process of health care (The Leapfrog Group, n.d.). Patient involvement and participation is also used by large health organisations to address potential ethical issues in research, or to improve ethical acceptability of decisions (Cotton, 2014, p. 51). Meanwhile, formal or informal patient organisations are established to facilitate patients in sharing experiences of illness and health, as well as

seeking support; e.g. Healthtalk in Scotland.

The other important aspect is public involvement promoted in some countries to democratise health policy-making and service planning at the state and sub-state levels. For example, Brazil successively held the national and local health conferences to deliberate the design of health policy with the participation of policy-makers, health workers, health providers and the general public (Participedia, 1992). In Canada, some democratic innovations were established to stimulate citizen participation in health service designs and policy-making, such as Residents' Health Services Panel for St. Michael's plan (Participedia, 2016) and Citizens' Dialogue on Public Health Goals (Participedia, 2005).

Laws and regulations have been enacted to ensure the collective involvement in health policy-making and planning at state and local levels in the UK. Patient organisations were established between 1974 and 2003, such as Community Health Councils (CHCs), patients' forums and Foundation Trusts (FTs)². These organisations were legitimised for collective involvement, which was enacted into acts and bills in primary care, community services and hospital sectors within the NHS system, such as the Health and Social Care Act in 2003. In Scotland, duties of public involvement and participation at the collective level have become one of the key functions of administration. For instance, the Scottish Health Council was established to support NHS Boards in involving Scottish people in designing and delivering health services.³ The programme of 'Our Voice' was established to support and promote patient and public involvement in the health sector (Thompson, 2020, p. 58). The principle of involving citizens is equality, which ensures access and impact are both equal in the process of public involvement.

2.5 The Chinese context

While patient rights and patient involvement become central in health policies and legislation in Western countries, theoretical and empirical studies have

² CHCs and patients' forums were abolished in 2000 and 2011.

³ The Scottish Health Council has now changed its name (from April 2020) to: Healthcare Improvement Scotland-Community Engagement.

been scant in developing countries. This does not mean that patient rights and involving patients are not vital in those countries. Rather, it should be no less important than in developed countries, given that patient groups are more vulnerable with a lack of competence in health literacy and capacity to engage with professionals. This study focuses on a new case, that of China. As the biggest developing country with the largest population in the world, China pursues an ambition to develop a mature health system for the public, which undoubtedly provides a perfect case for exploring the issue of patient involvement and participation. Moreover, it initiated a nationwide health system reform since 2009 after over 30 years of the marketisation of health care with ambitious objectives of providing every Chinese citizen with accessible, safe, effective, convenient and low-cost services by 2020 (Süssmuth-Dyckerhoff and Then, 2017, p. 137). Therefore, this study begins with the exploration of patient involvement and participation in a new context; i.e. a new country and a new health system. The section will briefly outline the new context in China. I will discuss in greater detail in the following chapters.

2.5.1 Health system in China

China has experienced enormous transitions in the economic and social sectors since the late 1970s (Hesketh and Zhu, 1997, p. 1543). Significant changes took place in the health sector: financial responsibilities have been rearranged among five levels of governments and more fiscal decentralisation is given to sub-state governments (Shen et al., 2012). Individual arrangements play a more important part in health service provision, instead of collective arrangements; market tools have been used to provide a range of public services; some departments of the public sector have been privatised (Meng et al., 2004, p. vi).

According to Meng et al. (2015, p. 16), the Chinese health system has three sub-systems: 'a health financing system, a health service delivery system and a health supervision system'. There are three main sources of health financing: 'government expenditure, social expenditure and out-of-pocket payments' (ibid., p. 66). Public hospitals and public health facilities deliver the majority of health services, consisting of health service delivery system and public health system (Liu et al., 2006). Private health providers are also

a major part in the health service delivery system, but they do not hold predominant roles. Health supervision is operated by health authorities at all levels.

The health administration body has a four-level hierarchy: the National Health and Family Planning Commission (NHFPC, formerly Ministry of Health until 2013) is the administrative body at the state level; provincial, prefecture/municipal and county health bureaus are health authorities at each level (Meng, 2015, p. 16). In the period of health system transition, most of the legislation and policy-making have been made by the central government. NHFPC is responsible for health policy-making and planning. Other departments, such as the Ministry of Civil Affairs (MOCA), the Ministry of Finance (MOF), the Ministry of Human Resources and Social Security (MOHRSS), share relevant responsibilities. The four levels of local government (province, prefecture/municipal, county and township) only play a limited part in health policy-making and service planning, although decentralisation was implemented with six rounds of administrative reforms between 1982 and 2013 (Xue and Zhong, 2012, p. 287). Local governments are mostly implementing policies, organising and regulating health services.

China is now undergoing a marketised health system with a social security net. The medical insurance schemes are financed by government subsidies, employers and individual contributions. Each scheme has different reimbursement rates, depending on medicine items, service types and individual condition.

There exist three types of health insurance scheme between 2003 and 2016: the Urban Employee Basic Medical Insurance (UEBMI), the Urban Residents Basic Medical Insurance (URBMI) and the New Cooperative Medical Scheme (NCMS). The UEBMI was carried out nationwide in 1998 and provided insurance to the urban working populations (Burns and Huang, 2017; Huang et al., 2015). In 2003, the NCMS was launched to cover partial health spending for the rural dwellers as a 'mutual-aid medical scheme' (Fang, 2018, p. 54). In 2007, the URBMI was established to cover the urban unemployed populations, including 'the students, children, the elderly, poor, and disabled' (Burns and Huang, 2017, p. 57).

Since 2016, the government has merged NCMS and URBMI in some pilot regions, attempting to fill the gap between NCMS and URBMI standards (Süssmuth-Dyckerhoff and Then, 2017, p. 139). In this study, I use Residents Basic Medical Insurance (RBMI) to refer to the new merged scheme. I categorise users of URBMI and NCMS in one group, as it covers a certain percentage of health costs for the rural dwellers, self-employed and the unemployed populations, who have a rather poorer insurance status. In other words, URBMI offer a more comprehensive and generous package than RBMS (Wang et al., 2016, p. 125).

2.5.2 Chinese health system reforms

There were several stages of health system reforms when the Chinese Communist Party held power in 1949. The first stage involved a central planned system between 1949 and 1978. The Chinese central government developed a central planned and managed system in rural areas and urban health insurance schemes, as well as mass campaigns as strategies to improve preventive and public health (Burns and Huang, 2017, p. 39). This was replaced by a socialist market model when the economic reform was initiated in 1978. The first character of the model is that it decentralises fiscal and administrative responsibilities to local governments. Specifically, the central government began to cut the redistribution of intergovernmental finance and shifted more spending responsibilities to lower levels of government in the tax sharing reform in 1994. This leads to a changed role of local governments from a service provider to a financier and provider (Shen et al., 2012, p. 10).

Meanwhile, administrative reforms are carried out to decentralise administration to sub-state governments (Xue and Zhong, 2012, pp. 296–297). As a result, local governments have more responsibilities and pressure to deliver public services. Each level pushes fiscal responsibilities down to the lower levels, failing to stimulate the willingness of providing health services at the grassroots levels, such as county and township health facilities (Burns and Huang, 2017, p. 61). The second character of the model is that policies at this stage encourage a free market in health care. For example, the central government issued ‘the Report of Health Reforms and Policies’ (Guanyu weisheng gongzuo gaige ruogan zhengce wenti de

baogao) in 1984, encouraging the governments to reduce the complexity of the administration and empower hospitals with more autonomy (Jianzheng fangquan) (Journal of People's Political Consultative Conference, 2015). The year of 1992 saw the official starting point of 'marketisation', as the State Council issued a document of 'Instructions on Health Reforms' (Guanyu yiliao gaige de zhishi) (ibid.). The issue opened up public hospital reforms, emphasising self-sufficient in finance, competition in prices and profit-seeking behaviour of services and medicine, beyond a small proportion of regular medical services. Mechanisms of competition were introduced between private and public providers; privatisation of ownership was promoted in health services. Privatisation was rapidly implemented by local authorities, and numerous grassroots health facilities as primary care providers were sold. Dummer and Cook (2007, p.12) indicate that accessibility is the biggest problem for rural residents, and 'access is governed by the ability and willingness to pay.'

Overall, the health system reforms between the 1980s and 2003 were regarded as a failure of health governance, as China ranked 144th in the evaluation of health improvement by WHO in 2000 (World Health Organization, 2000). It was also the source of the Severe Acute Respiratory Syndrome (SARS) as a public health crisis in 2003 (Huang, 2013, p. 5). More seriously, the out-of-pocket spending became the main source of health spending, which led to a shift from public finance budgets to family budgets (Tam, 2010, p. 65). As a result, many families went bankrupt due to the excessive health care spending. Duckett (2011) remarked that the state retreated from its role in health care between the 1980s and 2003. Meanwhile, the rising health care spending and profit-driven incentives reshaped the relationship between professionals and patients, which challenged health care practices and health system reforms (Pan et al., 2015, p. 149). 'Defensive medicine' and 'over-prescription' were common in Chinese health care practices, resulting in a vicious cycle of mistrust in the relationship (He, 2014, pp. 65–66). 'Inaccessible and unaffordable health care' (kanbingnan, kanbinggui) drew much political attention by Chinese policy-makers (Yip and Hsiao, 2015, p. 56).

In this regard, a serious government and public debate took place as to where the Chinese health system was going since 2005. Kornreich et al.

(2012) document various consultations before the announcement of the 2009 health system reform, which include academics, international organisations, the mass media, health professionals and managers, as well as the general public. Lv (2015) documents that a policy entrepreneurial coalition influences health policies after the outbreak of SARS in 2003, and it includes experts, the media and international organisations. However, this does not achieve a consensus as to how hospital services should be delivered, despite the recognition that the Chinese government would provide public finance for the basic health services, primary and preventive health care, through a network of health facilities at the grassroots level (Yip and Hsiao, 2015, p. 57).

In January 2009, the State Council announced a new reform with the main focus on access and affordability. The priorities of the reform included the expansion of medical insurance, the establishment of medicine supply security, the development of medical service provision, the provision of public health services and the reform of public hospitals (Süssmuth-Dyckerhoff and Then, 2017, pp. 137–148). However, the reform in 2009 proves ineffective in many aspects: the waste of inputs; the ineffectiveness of controlling for-profit behaviour in public facilities and physicians; inequalities; insufficiency of preventive health and disease control; the shortage of human resources (Yip et al., 2012, p. 840). Burns and Huang (2017, pp. 60–64) also point out that government subsidies remain low to support the operation of public hospitals, nor does the government tackle issues of efficiency and quality of care. However, the central government has been actively promoting the development of private health providers and encouraging more social investment in building more private health facilities since 2013 (State Council, 2013; General Office of State Council, 2015a). In this regard, marketisation and privatisation are still the main discourse in the Chinese health system, despite an improvement of the social security net and accessibility.

2.6 Research questions and objectives

This study mainly focuses on the micro-level interaction of professionals and patients in the hospital setting. It enables a closer look at provider-user engagement in the health care delivery on the ground. It chooses a bottom up approach to observe and understand the undergoing policies and medical

practices, as ‘street-level’ politics and bureaucrats who deliver policies and services have a great influence on policy-making and implementation (Lipsky, 1980). As Lipsky remarks (1980, p.4), ‘the ways in which street-level bureaucrats deliver benefits and sanctions structure and delimit people’s lives and opportunities. These ways orient and provide the social (and political) contexts in which people act’.

The study aims to provide a comprehensive understanding of patient involvement and participation by focusing on the case of China, which has been largely overlooked by the existing relevant literature. Two presuppositions are proposed before we begin the discussion: (1) in health care, patient involvement is desirable and achievable; (2) patient involvement only has meanings when it is desirable for patients in specific contexts. Drawing upon the theories of governance, citizenship and co-production, this thesis seeks to answer the following research question:

What does patient involvement and participation mean in Chinese hospitals?

To address the research question, I propose three additional sub-questions:

1. To what extent are patients involved and wish to be involved in their health care?
2. Within which contexts do patients wish to be involved?
3. How do these contexts, economic and socio-demographic conditions impact on how users wish to be involved in their health care?

The first sub-question aims to examine the taxonomy of patient involvement and participation in China. I explore the actual involvement and desired levels of involvement in the process of health care delivery, especially in the aspects of information-seeking and decision-making. The second sub-question aims to investigate the contexts of involvement, including macro- and meso-level political/policy/institutional contexts, and economic and socio-demographic conditions, based on the current literature and empirical evidence in the fieldwork in China. The third sub-question aims to explore why patient involvement and participation are not supported by policies and widely promoted across the system, and how various economic and socio-demographic conditions impact on users’ willingness for involvement.

Overall, the research uses ‘patient involvement and participation’ as a lens to probe the relationship of service providers and users in the delivery of health care in China. Drawing upon the existing theories of governance, citizenship and co-production, the study is designed to provide a comprehensive view of patient involvement and participation in the fast-changing context of China. It attempts to contribute to the understanding of the contextualised factors of patient involvement and participation in China.

2.7 Concluding remarks

This chapter provided the theoretical foundations of the study. Drawing upon the theories of governance, citizenship and co-production, I focus on a new context, that of China, which is very different from the developed democracies in Western countries. I explore the practice of patient involvement and participation in China and propose three research questions in order to investigate what the current state of play is and why it is like this. This enables a better understanding of relevant issues, including patient rights, patient roles in health care delivery and the professional-patient relationship. It also increases our knowledge of how much patient involvement and participation is promoted beyond the mature and developed health systems in the world. The following chapters will discuss the research design of the study, the analysis of the empirical data, and the discussion of the results and findings of the study.

Chapter 3 Research Design and Methodology

3.1 Introduction

This chapter elaborates the research design and methodology of this thesis. Section 3.2 introduces the core rationale for the research design focusing on interpretivism as the philosophical basis of social inquiry, case study design and qualitative methods as research strategies. It then outlines interviews and documents as the adopted methods in the data collection process. Section 3.3 provides an explicit overview of data collection procedures for service user interviews and other stakeholder interviews. It justifies the rationale of the sampling design and gives a picture of the achieved sample. It provides details of fieldwork including preparation, access, documents and interviewing. It explains why there are missing values in the first stage of fieldwork. Section 3.4 illustrates the process of data analysis, including data management, abstraction and interpretation. Section 3.5 considers and elaborates on the ethical issues. Section 3.6 discusses the criteria of reliability and validity. Section 3.7 explains the scope and limitations methodologically.

3.2 Research design

3.2.1 Ontology and epistemology

The research adopts interpretivism as a philosophical foundation of social inquiry. The social phenomenon of ‘patient involvement and participation’ needs to be better understood and developed in a new context. The ontology of assumptions is idealist, meaning that social reality consists of shared interpretations by social actors, which are produced and reproduced through their everyday lives (Blaikie and Priest, 2017, pp. 38–40). The epistemology of assumptions is constructionist positing that social reality has to be discovered from the ‘inside’ (ibid.). Taking the approach of social inquiry enables me to identify the ideas of service users and other stakeholders to generate the understanding of involvement and participation in the delivery of health care (ibid.).

The logic of inquiry uses an abductive approach. According to Blaikie (2010, p. 19), ARS is different from other logics, as the discovery starts from the accounts social actors provide. The abduction is seen as ‘a reasoning habit’, that old beliefs are of no help to understand social phenomena and ‘new beliefs must be brought into the world’ (Flick, 2014, pp. 127–128). As there is little existing knowledge of patient involvement and participation in China, new knowledge and theories have to be obtained in the new contexts abductively. Therefore, I identify lay concepts and meanings of patient involvement and participation in the process of investigation at the first stage of fieldwork. Typology and abstraction are interpreted through social scientific accounts and tentative hypotheses are generated in this discovery phase. Then, in the testing phase, data are collected and analysed to verify or falsify hypotheses at the second stage of fieldwork. More specifically, the analysis involves an exploration of the political, policy, institutional and individual contexts via abduction in the first stage of data collection. Then deduction proceeds in the second stage of data collection. However, I do not intend to show the analysis of the first stage for all sets of contexts before analysing confirmatory interviews in the second stage. Instead, I analyse each set of contexts to keep the same material in focus in each chapter (Chapter 4, 5 and 6), and then bring it all together in the discussion chapter (Chapter 7).

3.2.2 Research strategy: case study design and qualitative research

The research adopts the case study method to understand the issue of patient involvement and participation in the Chinese context. I use a qualitative methods approach within a case study design to conduct the research in China, where the issue has rarely been addressed systematically by social scientists. Drawing upon the theories of governance, citizenship and co-production, the research design attempts to incorporate theoretical ideas within data collection. The theories of governance help to explore the position of service users in the interactions with service providers, particularly health professionals. The theories of citizenship help with the investigation of how patients get involved in practice. The theories of co-production seek to explore the forms and desirability of involvement in health care delivery for patients.

3.2.2.1 Case study design

The research chooses the case study method to explore the meaning of patient involvement and participation in the real-world context. The rationale for choosing the case study method is as follows: firstly, it is not possible to control behavioural events, as they take place in a natural setting; secondly, the focus is on a contemporary phenomenon, rather than a historical one; thirdly, the boundaries between the phenomenon (patient involvement and participation) and contexts (political, policy, institutional, individual, cultural and social) are not clearly evident, as the phenomenon is in the real-world context; lastly, the complexity of the context in patient involvement and participation offers more variables of interest than data points (see Yin, 2014, pp. 4–12).

The research adopts a multiple-case design with three hospital-based cases in Shandong Province, the eastern part of China. The cross-case study allows a detailed and in-depth description and explanation of the involvement process. It is a holistic design with three case sites; i.e. a teaching hospital and a non-teaching hospital at the city level, as well as a non-teaching hospital at the county level (see Figure 1). By selecting teaching and non-teaching hospitals, I investigate whether or not there is a significant difference in types of hospitals and patient involvement, as professionals in teaching hospitals are more likely to promote patient involvement due to the knowledge of transferability at the global and state levels (Silber et al., 2020, p. 743). Meanwhile, the choice of hospitals at different levels enables access to different service users. For instance, city hospitals have service users from both urban and rural areas, while county hospitals have more service users from rural areas. The rationales for multiple-case design are: (i) multiple cases are more robust; (ii) multiple-case design with 2 or 3 cases follows the logic of literal replication (Yin, 2014, p. 57). Notably, the replication logic predicts similar results across 3 cases in the investigation.

Three cases are selected in Shandong Province, the eastern part of China. This is based on the practical issue of accessibility to resources, as I have developed a strong social network when I lived and studied there in the past

few years. Two hospitals are located in Jining City, which has a population of approximately 8 million people. The first selected case is the Affiliated Hospital of Jining Medical University. It is a teaching hospital with 79 clinical departments, 2.56 million outpatient visits, and 0.13 million in-patients in 2016. The second selected case is Jining First People's Hospital. It is a non-teaching hospital with 55 clinical departments, 0.24 million outpatient visits and 0.16 million inpatients in 2016. The third selected case is Penglai County People's Hospital. It is also a non-teaching hospital with 28 clinical departments, 0.54 million outpatient visits and 0.09 million inpatients in 2016.⁴ Three case sites are chosen in one province in order to minimise contextual variability at the regional level that might affect the investigated relationships (Kaarbo and Beasley, 1999, pp. 379–380). I do not include more cases due to the issue of institutional comparability. These selected cases are the only comprehensive hospitals in the case sites.

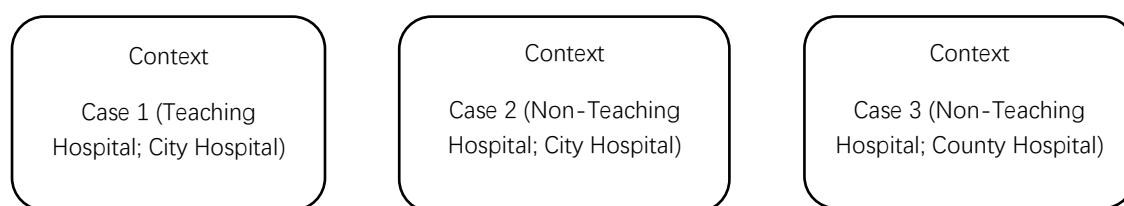


Figure 1 Multiple-case design (holistic)

In the case design, various subgroups are compared within the cases. It considers how different types of illness affect levels and mechanisms of patient involvement and participation. Therefore, patients are divided into three categories: those with chronic conditions; cancer patients who typically are in transition between acute and chronic phases; those with acute conditions. The rationale for grouping three types of patients is that research findings reveal that there are significant differences in patients' demand for involvement between chronic disease and acute disease in the treatment process (Thompson, 2007, p. 1307). I choose patients who have coronary heart disease in the Cardiology Department, breast cancer patients in the Thyroid and Breast Surgery Department, patients with acute intestinal tract disease in the Gastric and Intestine Department and patients with accidental

⁴ The statistics were collected through gatekeepers in three selected hospitals in the year of 2016. It is the time point when I start to conduct interviews of service users.

injury in the Emergency Department. The considerations of choices include previous research findings (Blanchard et al., 1988; Gaston and Mitchell, 2005; Schain, 1980; Sutherland et al., 1989) and access to patients. The study is a cross-sectional one, thus comparison is made at a single point in time. The unit of analysis refers to service users in health care delivery. However, the research does not intend to offer a statistical generalisation. Rather, it seeks to contribute to a theoretical generalisation, which draws conclusions from the study for a wider and more general application in other settings (Ritchie et al., 2014, pp. 348–354).

3.2.2.2 Qualitative research

This is a qualitative research project. I adopt the qualitative approach due to the focus on an under-researched topic in the new context. Rather than dealing with numbers and distribution, a qualitative strategy helps to look at the 'information expressed in words' (Walliman, 2006, p. 130), understanding the contexts that give meanings to patient involvement and participation, with focuses on descriptions, beliefs, opinions, values and behaviours. Hence, I use a qualitative approach in data collection and the analysis process in the research. At the first stage, I conduct interviews using open-ended questions to help understand contexts, concepts and theories of the research topic. Then qualitative theory is firstly devised after data collection, using the logic of abduction. At the second stage, I conduct qualitative data collection to test the theories. Theory refinement is complete after data analysis in the second phase.

3.2.3 Methods

3.2.3.1 Individual interviews

Compared to other qualitative approaches, interviews are regarded as the unique technique to 'take adequate account of the complexities and contradictions' (Ritchie et al., 2014, p. 179). Interviewing helps create and interpret the accounts of social actors, as well as understand the context of social interactions in which they have been involved (Blaikie, 2010). For subject matter, interviews allow the researcher to understand complex

processes and issues and explore 'private subjects or those involving social norms' and 'sensitive issues' (Ritchie et al., 2014, p. 59). In social sciences, interviewing is described as the 'conversation with a purpose' (Webb and Webb, 1975, p. 130). In the conversation, knowledge is produced through collaboration between the researcher and interviewees. The relationship between the researcher and the interviewee can be defined as a 'conversational partnership' which is responsive, reciprocal and based on mutual trust (Rubin and Rubin, 2005, pp. 79–107). This requires high personal and professional qualities of the individual interviewer, including active listening and curiosity, as 'they are themselves considered research instruments and as such can influence the interaction' (Ritchie et al., 2014, p. 184).

I employ semi-structured interviews with a list of themes to ensure the reliability and validity of data, given the function of minimising procedural reactivity and enabling free exploration of meanings and beliefs. Moreover, it creates a naturalistic setting, which is considered to be ideal, and embraces "the 'feeling' of the unforced conversations of everyday life" (Wilson and Sapsford, 2006, p. 95).

3.2.3.2 Documents

In this research, I use documents in conjunction with interviews in the process of data collection. Policy documents are interrogated to identify patterns of relationships between the service users and providers, as well as the contexts of patient involvement and participation. Primary sources, including government reports, official and unofficial reports, and statistical collections form the essential and initial material for providing the raw evidence (Finnegan, 2006, pp. 141–142), which are directly used by the researcher. Sources of data are mainly obtained from the government and hospital website portals and published documents.

3.3. Data collection

3.3.1 Data collection procedures for health service users

The main type of data in this research is primary data. Primary data are generated through the interviews to control the process of data production and ensure the quality of data. A small number of secondary data are generated, including policy documents and archived data sets, as well as books and journals in libraries. The primary data come from the natural social settings, which is regarded as 'the result of direct contact between a researcher and the source' (Blaikie, 2010, p. 160). In this research, service users, mainly patients, are social actors who play significant roles in the process of health care delivery.

3.3.1.1 Study population and sample frames

1. Study population

The study population in the research is defined as 'health service users' in China. The central population are patients and lay carers who use health services in public hospitals. Their experiences and views of health service delivery offer insights into the social enquiry. Potential service users are excluded from the scope of enquiry, as they are not involved in specific circumstances, such as diagnosis, treatment and post-treatment. Furthermore, a supplementary population of past patients, who have received treatments in health facilities, are also included, such as some patients who are undergoing re-examinations.

2. Sample frame

The sample frame is generated from the gatekeepers in public hospitals in China. As I am working with health service providers, it is a very effective way to generate a sample frame for patient groups I am looking for. The gatekeepers include hospital managers and medical professionals in each selected department. Gatekeepers help to identify potential patients who meet the criteria (i.e. health insurance status, disease type, age). They firstly

exclude those who are physically and/or psychologically incapable for interviews, and those who are not told about their condition or illness by family members or professionals. Then they introduce the study and my details ward by ward. Afterwards, I go to the wards to ask if they are willing to participate in my interviews. Thus, it is a very useful way to develop a sample frame by gatekeepers, by meeting the need for diversity and 'making sure the sample meets the required criteria' (Ritchie et al., 2014, p. 126).

3.3.1.2 Sampling design

When interviewing health service users, the research adopts a two-stage, non-probability method of sampling: the convenience sampling at the first stage and purposive sampling at the second stage. Instead of random sampling, I adopt non-random methods to obtain data. The main reason is that non-random methods present the most suitable strategy for qualitative studies, allowing the selection of units with particular features of the study population (Ritchie et al., 2014, p. 113). However, it is noted that non-probability sampling has heavy restrictions on further conclusions due to 'its *lack* of generalisation in the sense of being representative of a larger population' (Maxwell, 2009, p. 245).

1. Sampling at Stage 1

I choose the convenience sampling approach to identify the available sample at the first stage. As sample units are selected based on who is available, the purpose of convenience sampling is obtaining early information about the three cases within a short period (Ritchie et al., 2014, pp. 115-116). Yet, convenience sampling is questioned for its lack of diversity (ibid.). Ritchie et al. (2014, p. 116) propose two principles of sampling: 'symbolic representation' of sampling units and 'diversity' of the defined population. In this study, diversity is important, as it enables the opportunities of identifying the full range of factors that influence the willingness and actual involvement behaviour. In this regard, I ensure the inclusion of various sampling features in the sampling process. I consider and select sample units according to socioeconomic characteristics (i.e. age, health insurance type) and type of

disease. I prioritise type of disease and health insurance type as my primary criteria, and age as secondary. Gender is excluded, as in some cases it may be closely linked to the type of disease, e.g. women and breast cancer; men and heart disease⁵.

To avoid the overlap of the sample, I indicate a note at the front of the informed consent that the potential participants should abstain from the interviewing if they have already participated. This is also applicable for those who are not patients who use health services, such as lay carers.

如果您不是医疗服务的用户，请不要参与访谈。如果您已经参与过访谈，请不要再次回答。(If you are not a service user who receives health services, please DO NOT take part. If you have already participated, please DO NOT answer questions again.)

I divide interviewees into 3 groups by disease-type: chronic disease; cancer; acute disease. I also group interviewees by health insurance type: UEBMI and RBMI. Health insurance type is an important indicator of socioeconomic status: people with UEBMI have better welfare in health services, compared to those with RBMI. I also divide age into 3 groups: 18 to 50 years; 51 to 65 years; 66 years and above. I group those who are 66 years and above as the elderly, who are often frail and more susceptible to various diseases. I group those who are between 51 and 65 years old as a relatively younger group (or the middle aged), as many of them are working and are likely to suffer from specific diseases, such as coronary heart disease and breast cancer. Those who are under 50 years old are identified as a healthier, younger and mostly working group. This group has a smaller chance of having certain diseases, such as breast cancer and coronary heart disease, but may be more likely to have other problems, such as accidental injury and gastrointestinal difficulties. This is mainly due to the nature of the work and risk-taking behaviours, which are more likely among younger people.

^s Smoking is highly associated with the incidence of coronary heart disease of men, as over 60% of Chinese men are smokers (Long et al., 2020; Zhang et al., 2008, p. 1127).

Four clinical departments are sampled in each of the three hospitals: the Cardiology Department, the Thyroid and Breast Surgery Department, the Gastric and Intestine Department, and the Emergency Department. The sample units in each department come from a singular (or similar) type of disease; e.g. all the sample units in the Cardiology Department are patients with chronic heart disease; all the cases in the Thyroid and Breast Surgery Department are patients with breast cancer (mostly women); all the cases in the Gastric and Intestine Department and the Emergency Department are patients with acute disease.

The original sample requires around 10 participants in each department for Case 1 and 2, and 5 participants in each department for Case 3. This is because Hospitals 1 and 2 are larger than Hospital 3: the number of beds in each department in Hospitals 1 and 2 is between 30 and 60; the number of beds in each department in Hospital 3 is 10 to 40.⁶ As I intend to have a target size of 100, I planned to have 40 interviews respectively in Hospitals 1 and Hospital 2, and 20 in Hospital 3. Each department in Hospital 1 and 2 includes 10 interviews, and with 5 interviews in each department in Hospital 3.

2. Sampling at Stage 2

At the second stage, I choose purposive sampling, as it enables me to select sample units with particular features or characteristics for detailed exploration and understanding of the research questions (Bryman, 2012, pp.188-190). The criteria for selecting sample units include types of disease and health insurance type. I firstly stratify the sample by disease-type, with chronic condition, breast cancer and acute condition. Then I stratify the sub-groups by health insurance type, with UEBMI and RBMI users. I exclude the criteria of age, as it is correlated with chronic/ acute disease in many cases.

⁶ In Hospitals 1 and 2, the Cardiology Department, which is the largest clinical department, has around 60 beds, while the Thyroid and Breast Surgery Department, which is the smallest, only has round 30 beds. In Hospital 3, the largest department is the Cardiology Department with 40 beds and the smallest is the Emergency Department with only 10 beds.

For example, most interviewed patients with coronary heart disease (chronic conditions) are over 50 years old, and few patients in the young age group can be found in the sample. In terms of breast cancer, most interviewed patients are between 35 and 55, and women over 60 years old are fewer than the middle-aged.

The original design is 60 cases in total. The sample size requires 8 respondents in each category of disease-type for Cases 1 and 2, and 4 respondents in each category of disease-type for Case 3. In particular, 4 urban employees and 4 unemployed are needed in each category for Cases 1 and 2; 2 urban employees and 2 unemployed are required in each category for Case 3.

Notably, the research design is not intended to map the associations between gender and condition. This is because a number of conditions are more or less specific to one or other gender, such as breast cancer (women) and coronary heart disease (men). Therefore, the study cannot draw conclusions about the association between gender and condition.

3.3.1.3 Achieved sample

The achieved sample is 155 interviews with service users (148 patients and 17 carers). I conduct 95 interviews at the first stage and 60 interviews at the second stage. The following section illustrates the profiles of interviews in the two fieldwork settings.

1. Profile of fieldwork at Stage 1

Interviews are conducted with 95 service users in three hospitals (see Table 1). The population sample is 95, as all the participants meet the required conditions that they are using health services in the hospitals. As I use a convenience sampling strategy, the sample size is not the same in every case: 40 for Case 1, 35 for Case 2 and 20 for Case 3. In terms of clinical

departments, there are 37 interviewees in the Cardiology Department, 26 in the Thyroid and Breast Surgery Department, 17 in the Gastric and Intestine Department, and 15 in the Emergency Department. After the completion of 95 interviews, there comes a point of diminishing return where increasing the sample size no longer brings in new evidence (Ritchie et al., 2014, p. 117). Thus, I stop collecting data at this point.

Table 1 Interviews by hospital and department

		Department				In total
		Cardiology	Thyroid and Breast Surgery	Gastric and Intestine	Emergency	
Hospitals	Case 1	23	9	5	3	40
	Case 2	7	11	7	10	35
	Case 3	7	6	5	2	20
In total		37	26	17	15	95

Source: Author's own data

Missing Cases: 0

In some cases, interviews involve patients' lay carers (normally their family members) when patients are having a treatment, feel uncomfortable, or are unsure about the question. It is helpful for data collection, as lay carers usually know exactly what happens and they can provide details and views on specific issues. In order to distinguish views from different perspectives, I conduct interviews when patients are there. I ask carers if the views are agreed or actions are approved by patients themselves, and repeat questions to patients when they are available. Overall, 7 interviews involve lay carers, and patients also give responses regarding specific questions (See Table 2).

Table 2 Interview respondents-Stage 1

	Patients	Carers	In total
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Hospital	Case 1	35	5	40
	Case 2	33	2	35
	Case 3	20	0	20
In total		88	7	95

Source: Author's own data

Missing Cases: 0

In terms of the distribution of the disease-type (see Table 3), 37 interviewees are patients with chronic conditions; 32 cases are patients with acute conditions (mainly gastrointestinal disease and accidental injury); 26 respondents are cancer patients (breast cancer).

Table 3 Interviews by disease-type and hospital

		Disease type			In total
		Chronic disease	Cancer	Acute disease	
Hospital	Case 1	23	9	8	40
	Case 2	7	11	17	35
	Case 3	7	6	7	20
In total		37	26	32	95

Source: Author's own data

Missing Cases: 0

Age groups are combined into three categories: 50 and below; between 51 and 65; 66 and above. As shown in Table 4, 36 out of 95 interviewees are service users under 50 years old; 34 interviewees are between 51 and 65 years old; 25 interviewees are 66 years old and above.

Table 4 Interviews by age group and hospital

	Age Group			In total
	18-50	51-65	66 +	

Hospital	Case 1	15	14	11	40
	Case 2	18	9	8	35
	Case 3	3	11	6	20
In total		36	34	25	95

Source: Author's own data

Missing Case: 0

In terms of the distribution of the health insurance type, 93 cases are valid and 2 cases have missing data.⁷ 53 sampled interviewees are RBMI users who have no job; 40 are UEBMI users (see Table 5).

Table 5 Interviews by health insurance type and hospital

		Health insurance type		In total
		UEBMI	RBMI	
Hospital	Case 1	19	21	40
	Case 2	18	15	33
	Case 3	3	17	20
In total		40	53	93

Source: Author's own data

Missing Cases: 2

In terms of the distribution of gender (see Table 6), 44 interviewees are male and 51 respondents are female. Notably, all sampled patients with breast cancer are female.

Table 6 Interviews by gender and hospital

		Gender		In total
		Male	Female	

⁷ Two interviewees claim that they have no idea what kind of health insurance they have.

Hospital	Case 1	22	18	40
	Case 2	13	22	35
	Case 3	9	11	20
In total		44	51	95

Source: Author's own data

Missing Cases: 0

2. Profile of fieldwork at Stage 2

Fieldwork at the second stage is conducted with 60 interviews in three hospitals (see Table 7). The population sample is 60 and all respondents meet the required conditions, in that they are in the process of health service delivery.⁸ The sample size of Case 1 and Case 2 is 24 in each, and Case 3 is 12. 20 interviewees are completed in the Cardiology Department, 20 in the Thyroid and Breast Surgery Department, 10 in the Gastric and Intestine Department and 10 in the Emergency Department.

Table 7 Interviews by hospital and department

		Department				In total
		Cardiology	Thyroid and Breast Surgery	Gastric and Intestine	Emergency	
Hospital	Case 1	8	8	4	4	24
	Case 2	8	8	4	4	24
	Case 3	4	4	2	2	12
In total		20	20	10	10	60

Source: Author's own data

Missing Cases: 0

⁸I also involve service users who are having re-examinations in the hospitals, such as patients with coronary heart disease and breast cancer. They are not having treatments for the first time, and they may recall and share previous experience.

There are 10 interviews with both patients and lay carers at the second stage of fieldwork (see Table 8).

Table 8 Interview respondents-Stage 2

		Patients	Carers	In total
Hospital	Case 1	22	2	24
	Case 2	20	4	24
	Case 3	8	4	12
In total		50	10	60

Source: Author's own data

Missing Cases: 0

As I purposively select patients with various types of disease, the numbers of interviews within each category of the disease-type are allocated equally: 20 interviews with chronic conditions, 20 interviews with breast cancer and 20 interviews with acute conditions (See Table 9).

Table 9 Interviews by disease type and hospital

		Disease-type			In total
		Chronic	Cancer	Acute	
Hospital	Case 1	8	8	8	24
	Case 2	8	8	8	24
	Case 3	4	4	4	12
In total		20	20	20	60

Source: Author's own data

Missing Cases: 0

As I intend to see whether insurance type affects the attitudes and willingness for involvement and participation, I purposively select sample

units as the employed and the unemployed (including rural residents), with equal numbers within each category of disease-type (see Table 10).

Table 10 Interviews by health insurance type and disease-type

		Health Insurance Type		In total
		UEBMI	RBMI	
Disease-type	Chronic	10	10	20
	Cancer	10	10	20
	Acute	10	10	20
In total		30	30	60

Source: Author's own data

Missing Cases: 0

Like the first stage, three age groups are categorised: 18 to 50; between 51 and 65; 66 and above. As shown in Table 11, 18 out of 60 are interviewees below 50 years old, 27 interviewees are between 51 and 65, and 15 interviewees are over 66 years old.

Table 11 Interviews by age group and hospital

		Age group			In total
		18-50	51-65	66+	
Hospital	Case 1	9	10	5	24
	Case 2	5	13	6	24
	Case 3	4	4	4	12
In total		18	27	15	60

Source: Author's own data

Missing Cases: 0

In terms of gender distribution, 28 out of 60 interviewees are male, and 32 respondents are female (see Table 12). Notably, almost all respondents who have breast cancer are female, with only 1 male patient in the interviews.

Table 12 Interviews by gender and hospital

		Gender		In total
		Male	Female	
Hospital	Case 1	13	11	24
	Case 2	12	12	24
	Case 3	3	9	12
In total		28	32	60

Source: Author's own data

Missing Cases: 0

3.3.1.4 Preparation for fieldwork

The preparation for the fieldwork includes 5 pilot interviews, some discussions with the frontline medical staff and a version revision. In December 2016, 5 interviews were piloted in the Cardiology Department in Hospital 1 (Case 1). To maximise the need for diversity, the respondents include service users in different medical situations and socioeconomic status. Many interview questions are open-ended as it allows space for interviewees to talk freely. After the interviewing I have a review meeting with some medical staff, including doctors and nurses in the department. It is suggested that the language in some questions or ways of proposing questions need to change, as some interviewees could not understand specific academic terms. Then I make some revisions based on the pilot data, which includes a substitution of specific terms and a more natural ordering of topics.

3.3.1.5 Fieldwork: access and documents

Access in the fieldwork includes local hospitals and service users. The access to local hospitals is via gatekeepers in each organisation. According to the regulations of the hospitals, the researcher should make formal application to the hospital if he/she wishes to interview patients. Thus, I make an application and get approval from the top level of administration, and then work as an intern in the Quality Control Department/Human Resource Department in the hospitals.

As to access to patients, I get approval and is introduced by nurses in each department. The nurses pass my detailed information to patients and their families. In Hospital 1 and Hospital 2, I knock on the doors of every ward and ask for their willingness to participate in the study. I avoid disturbing those who are excluded by gatekeepers (see Section 3.3.1.1). I do not ask nurses to introduce potential respondents to me, as I attempt to avoid selection bias. However, it is different in Hospital 3, which is located in a small county with a large population of rural residents. I am told by my gatekeepers that it is difficult to access local residents, unless I am introduced by someone they know. Under these circumstances, my gatekeepers, mainly nurses in each clinical department, select potential respondents for me. It is special in small places within a Chinese context, as networks bring resources, which is crucial for access. To avoid a coercive approach for obtaining interview opportunities, I ask nurses to play the role of gatekeepers, instead of doctors. Doctors might be seen as part of the professional hierarchy with dominant power relationships over patients, compared to nurses who play the role of carers. I also encourage gatekeepers to be away from the wards or invite patients who are physically capable to walk to the interview rooms. My dialect proves to be beneficial here, as the key tool to access local people in the hospitals.

Documents are important to access the fieldwork. Documents include the brief introduction of the proposed research (both for interviewees and gatekeepers), the student identity, and a supporting statement from my supervisors.

3.3.1.6 Fieldwork: interviewing

During the interviewing, responses are recorded digitally or in a written form for later analysis.⁹ Informed consent are taken and the arrangements for confidentiality and disclosure are set out at the beginning of the conversation (see Appendix 5). In order to ensure the quality of data collection, I follow the six stages of the interview process elaborated by Ritchie et al. (2014, pp. 186–190): stage 1 is the arrival with social greetings and small talk; stage 2 is the introduction of the research topic, including the informed consent, explanation of the aims and objectives, the arrangement for confidentiality and disclosure, scope of the interview, and the flexibility of the answers; stage 3 is the acquisition of important contextual information such as the interviewee's age, gender, the type of disease and health insurance type; stage 4 is the breadth and depth of coverage; stage 5 is ending on a positive note; stage 6 is the after-interview stage, such as thanking the participants, explaining the usage of the data and reporting, as well as reflecting and gathering new information (see Appendix 1).

Contextual information is either observed (e.g. gender) or asked at Stage 3 of the conversation:

Age: *how old are you?*

Socioeconomic status: *What type of health insurance do you have?*

Education: *How many years of education have you had?*

To open up key topics of the research, I design a mapping question, making it possible to ask follow-up questions. The first question is proposed in the interview:

Can you share your experience of engaging with health professionals in the treatment process?

⁹ For some respondents who are happy with voice recordings, I record their interviews digitally. For those who do not want to be recorded, I ask my colleagues in the hospitals to record in words.

Responses to this question provide the researcher with part of the landscape, enabling the exploration of more details, such as discussion of treatment options, trust in doctors, patient's behaviour of seeking information and involvement in decision-making.

Afterwards, follow-up questions are raised for probing and prompting effectively. Probing techniques are used to develop what they have said, explain 'why people act, think, feel, react in the way they do', explore impacts, effects and consequences, understand fundamental values, views, or experiences, 'clarify language or terminology' and 'challenge inconsistencies' (Ritchie et al., 2014, pp. 194–196).

Some probing questions are prepared to explore and explain the attitudes and views of patient involvement and participation. For example:

Do you feel positive or negative when the doctor gives you several options of treatment?

How do you respond when you are given suggestions by your doctor?

Why do you think it is important that you need to ask your spouse to make decisions?

Using a range of prompts may stimulate participants to generate answers freely. For example, I ask a question as follows:

Some people talk about the importance of trust in their doctors, while others do not. Is it an issue for you?

3.3.1.7 Missing values

At the first stage of fieldwork, some missing values are identified in the

process of data collection. I do not delete the cases, as many respondents give valuable viewpoints for other questions. Questions to which interviewees do not respond include perceptions of professional-patient relationship, perceptions of seriousness of the illness and willingness for involvement and participation. This can be attributed to the nature of questions which respondents may see as sensitive or unclear. Some patients are unwilling to talk about professional-patient relationships when I prompt the topic, as they are accepting treatments from their professionals. The other questions, such as perceptions of seriousness and willingness for involvement in their health care, may be relevant to their uncertainty of conditions. For instance, a woman with newly diagnosed breast cancer is stressed about her condition and gives a response of 'unclear'. And some patients who are under the circumstances of an emergency do not really know how much they want to be involved.

To resolve the problems, I adjust my interview questions in the second stage of fieldwork. Instead of talking about professional-patient relationship or trust, I ask respondents whether or not they want to leave decision-making to professionals; why they do (not) involve their professionals in health care decisions. I get clear responses of seriousness of conditions in the second fieldwork, as I give four options to respondents (very serious, a little serious, so-so, nothing serious). In addition, I also repeat questions with no responses in the latter part of interviews and ask their family members for further responses. This process removes missing values in the second stage of fieldwork.

3.3.2 Data collection procedures for other stakeholders

To have a better understanding of Chinese contexts in a wider scope, I conduct interviews with other stakeholders in health service delivery, such as academics, local administrators, leaders of Non-government Organisations (NGOs), health board managers and health professionals. These stakeholders are very familiar with policy, institutional and political contexts in the Chinese health system and may offer insights into the issue. The interviews were conducted between 2015 and 2019, before and after the

first stage of fieldwork with service users. Most of the interviewees are from Shandong Province, as my personal network enables me to have access to potential respondents.

3.3.2.1 Sampling strategy

The selection criterion of sample members is someone who knows the political, policy and institutional contexts of patient involvement and participation in China. Local administrators, NGO leaders, academics, health professionals and health board managers are target sample members as they are close to policy-making and social activities.

'Snowballing' is used as an approach for the sampling frame due to the difficulty of identifying potential sample members who meet the selection criteria (Ritchie et al., 2014, p. 129). Therefore, I begin to sample from the academics at a local university, as some of them are working with local authorities and NGOs in the fields of policy and governance. Meanwhile, it is worthwhile to probe their views of the issues. Afterwards, some local administrators and voluntary groups are recommended to me as potential sample members. I contact them and obtain consent to conduct interviews. In addition, access is gained through gatekeepers to interview health professionals in various departments and health board managers in the selected local hospitals. The process of sampling adopts a single-stage, non-probability method. Convenience sampling is chosen to select members who are available.

3.3.2.2 Achieved sample

Overall, there are 19 interviews conducted in the fieldwork (see Table 13). I conduct 2 interviews with local administrators, a group of two officials working for the provincial health department and an administrator from the department of civil affairs in the city government. I also interview an NGO leader in a health-related field and 3 academics who work in the field of public policy and public services. There are interviews with 6 health professionals

(physicians and surgeons) and 7 health board managers in the selected case sites. The sampling process stops when no new member is generated.

Table 13 Achieved sample of other stakeholders

Stakeholders	Time (year, month)	Location
Academic	2015.10	Jinan
Academic	2016.1	Weifang
NGO: China-Dolls	2017. 2	Jinan
Local administrators (a group interview with two)	2017.2	Jinan
A local administrator	2018.5	Jinan
6 health professionals	2018. 7-2018. 8	Jining & Penglai
7 health board managers	2018. 9-2018.10	Jining & Penglai
Academic	2019.1	By telephone

Source: Author's own data

3.4 Data analysis

The research adopts the thematic analysis and the framework approach to manage and analyse qualitative interviews (Ritchie et al., 2014, pp.282-283). In terms of patient interviews, I use the framework approach to explore and interpret patterns and meanings of data on the case by case basis. I also use thematic analysis to map the dynamics of phenomena of patient involvement and participation, create taxonomies and find the associations between socio-demographic conditions and attitudes. In terms of interviews of other stakeholders, I use thematic analysis to produce textual data. In the following sections, I illustrate how I manage and analyse the empirical data.

3.4.1 Data management

In the process of data management, I first review the interview materials and identify themes and topics relevant to the research objectives in the

familiarisation stage. Then, I construct a preliminary framework for data organisation, based on the interview outline and independent analysis of 15% of the transcripts (see Table 14). I generate a list of topics with a hierarchy of themes and sub-themes for the data set. I develop 5 themes: individual attributes (A1); cultural and social contexts (A2); involvement in health care (A3); willingness for involvement in decision-making (A4); and others (A5).

Table 14 Thematic framework

<u>A1 Individual Attributes</u>
A10 Age
A11 Gender
A12 Type of Patient (Inpatient/Outpatient)
A13 Type of Disease
A14 Type of Health Insurance
A15 Perceived Seriousness
A16 Clinical Department
A17 Origin of Patient
 <u>A2 Cultural and Social Contexts</u>
A20 Cultural Capital
A200 Education
A201 Exposure to Mass Media and Written Material
A202 Use of Internet
A203 Qualifications of Health Care
 A21 Social Contexts
A210 Carer Details
A211 Family Involvement
A212 Social Capital
 A22 Views of Health System
A220 Choice for Health Service
A221 Rights of Choice and Voice
A222 Ideal Patient-Doctor Relationship
A223 Patient-Doctor Relationship in Reality
A224 Trust in Doctors

A225 Opinions of Current System
<u>A3 Involvement in Health Care</u>
A30 Knowledge of Condition Before Treatment
A31 Communication with Doctors
A32 Capacity of Engagement
A33 Perceptions of Treatment
A34 Views of Making Voices
A35 Attitudes Towards Negative News
<u>A4 Willingness for Involvement in Decision-making</u>
A40 Information Giving/Seeking
A401 Willingness for Information
A402 Demand for Information
A41 Treatment Decision-making
A411 Preferences over Involvement/Desired Levels of Involvement
A412 Preferred Involvement in the Process of Health Care
<u>A5 Others</u>

Source: Author's own data

Then, I use NVivo 11.0 to index the transcribed interviewing data according to the thematic framework. Afterwards, I conduct framework matrices to summarise and display data (see Table 15). The first column of the matrix is case identification with individual attributes, including age group, type of disease, gender, hospital, type of insurance. The first row of the matrix includes descriptive themes, including cultural capital, social contexts and views of health system. Each case has a particular row to enter and display materials.

Table 15 Example of the framework matrices for theme of cultural capital, social contexts and views of health system

	A: A 20 Cultural capital	B: A21 Social contexts	C: A22 Views of health system
1: 1101	I watch TV	My spouse looks	I am very happy

Age_Group = 66 above Type_of_Disease = Chronic Gender = Female Hospital = Jining First People's Hospital Type_of_Insurance = UEBMI	everyday and buy products that are advertised on the TV. I believe in my own ways of disease management, and I think it has good outcomes	after me when I am ill.	with the hospital, because I come here often and know everything well. I choose this hospital because it is close to my home. I trust the doctors. I think they are nice to me.
2: 1102 Age_Group = 66 above Type_of_Disease = Chronic Gender = Female Hospital = Jining First People's Hospital Type_of_Insurance = RBMI	I learn some relevant information about the disease.	My spouse and children take care of me. I don't discuss with other patients here, although we have similar symptoms and disease.	I think doctors and patients are quite equal. I feel the relationship is good.
3: 0203 Age_Group = 66 above Gender = Male Type_of_Disease = Chronic Hospital = Affiliated Hospital of Jining Medical University Type_of_Insurance = UEBMI	I only have primary schooling. I watch TV to learn health information. But I cannot access to the internet, because I don't know how to use it.	My daughter-in- law is a medical professional who works for Public Health Department, and she offers much help in the process of the treatment. I occasionally discuss with others about my	The hospital is very near my home. It is convenient and accessible, although there are other facilities to choose. I am OK with health services here. I believe doctors

		<p>disease, especially those who have similar disease and age.</p>	<p>and patients should be equal.</p> <p>In the reality, they are not very equal, I think. Doctors are professionals with which are consulted.</p> <p>I trust doctors myself, and I think patients should rely on doctors and follow doctors' instructions.</p> <p>I think health institutions are better in the planned system than in the marketised system, although we were all poor. This is because people pay for health services in the marketised system, but free in the planned system. For elderly people who have chronic disease, we spend so much money on medicine and</p>
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			health services, and it is really unaffordable.
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Source: Author's own data

3.4.2 Abstraction and interpretation

The full analysis is supported by NVivo 11.0. By using the thematic analysis and the framework approach, data are abstracted and interpreted to develop categories and describe classification. Firstly, it detects elements for different themes and identifies and orders key dimensions of patient involvement and participation. It also creates single-dimensional typologies such as cultural capital, social contexts, choice and voice, trust in doctors, decision-making experience. I use a central matrix in thematic analysis to map linkages and find associations between socio-demographic characteristics, subgroups, behaviours, desire, attitudes and beliefs.

Apart from description, I offer the analysis to explain and illustrate some questions: Why do patients have various levels of desire to be involved in their health care? What are the key factors that help explain willingness for involvement? The analysis helps to explore contexts of patient involvement and participation, by drawing upon the implications of description and explanations provided patients and carers.

3.5 Ethics

Potential ethical issues may arise in the process of data collection. There might be some potential risks of harm: pain, physical injury, psychological damage, material damage (see Traianou, 2014, p. 63). In this study, issues that are likely to arise include physical pain and psychological anxiety, as most of the participants are in-patients who are regarded as relatively weak, both physically and emotionally. Therefore, it is key to the selection process by the gatekeepers at the initial stage that all the participants should be in stable and conscious physical and psychological conditions.

Meanwhile, it is important to select patients who are aware of their illness or condition, especially those diagnosed with cancer. This is completed prior to the interviewing, by double-checking the information with nurses and family members. In addition, some questions in the interview are designed to avoid mentioning the specific disease. 'Cancer' is not mentioned by the interviewer in the conversation, unless patients talk about it first. Notably, although some interviews are conducted in the shared wards, it is a taboo for Chinese patients to discuss their conditions in public, unless they are willing to talk freely. Therefore, I propose the question in an open-ended way: Have you got any ideas of your condition before the treatment? Do you think you can express clearly about how you feel and your need? Do you understand the interventions the doctor has had on you in the process of treatment?

3.5.1 Confidentiality

The research does not intend to raise any accidental disclosure of the information. All interviews are conducted separately and independently. Some patient interviews in the shared wards are carried out separately; i.e. I use curtains to separate patients from others to assure the independence of interviews. To ensure the confidentiality of other stakeholders, such as professionals, managers and local administrators, the interviews are conducted separately in a room or on the telephone. I would not discuss any details of the study outside my research team, which includes my supervisors. The research findings would not be reported under any circumstances that can identify the participants. Meanwhile, personal information is stored separately from audio recordings and transcripts and each participant is assigned with a serial number in the research data.

3.5.2 Informed consent

The research obtains the informed consent from respondents before data collection. It provides the full information of the research to the participants, including research objectives and aims, the individual who conducts the study, rights of participants and data confidentiality and anonymity. The consent to tape or record is obtained before the interviewing.

I work with gatekeepers to obtain the consent to protect the vulnerability of patients. All the information is given voluntarily, and no direct or indirect pressure is put on the individuals to participate. In other words, patients and their families have complete freedom to decide whether to participate or not. For the format of the consent form, please see Appendix 5.

3.6 Reliability and validity

Concerning the generalisation of research findings, the issues of reliability and validity are considered in the research. In qualitative research, reliability is depicted as 'being thorough, careful and honest in carrying out the research' (Robson, 2002, p. 176). The wording of interview questions is reviewed by practitioners and readjusted in the interviewing process. The relationship between participants and myself is not hierarchical, as I tell them I am a PhD student and would appreciate their contributions to the research. I also talk to them about a range of topics to maintain a trusty and easy relationship. Therefore, I give a lot of attention to ensuring a careful handling of the fieldwork details, giving confidence that the qualitative study could be repeated.

In terms of the measurement validity, it is likely to be achieved because all concepts and analyses are built on previous research and the pilot study, so that measurements can capture meanings and relationships of concepts precisely. In terms of internal validity, reflexivity is used to reduce the risk of researcher bias. However, as the sampling strategy does not adopt a random selection process, the research cannot achieve an empirical generalisation. The findings of the study may not be applicable to other populations or other contexts. Nevertheless, further research is needed to achieve external generalisation due to the limitations of non-random sampling.

3.7 Scope and limitations

The research mainly focuses on the issue of patient involvement and

participation in the process of health care delivery. The analysis attempts to describe and explain relevant behaviours, desires, beliefs and attitudes of patient involvement and participation in the context of China. The boundary of time in the study is when the research is conducted between 2015 and 2019, with the past and future excluded.

The research is limited in scope by sample size and geographic area: 155 service users are interviewed in the data collection process and three hospitals are selected in the eastern part of China; 19 individual interviews of other stakeholders are conducted, including local administrators, university academics, an NGO leader, health professionals and health board managers. Meanwhile, the sampling strategy is only confined to convenience sampling, purposive sampling and snowballing, which leads to the limitations of the study findings. These issues are attributed to practical reasons, such as limited time and resources.

3.8 Concluding remarks

The chapter outlines how I design the research and choose an appropriate methodology to achieve the research objectives. I adopt a three-case design in the eastern part of China to follow a literal replication and a qualitative design to answer the research questions. I use individual interviews and documents for data collection. In terms of the study population, I define it as 'health service users' and 'other stakeholders' in China. The sample frame is generated from gatekeepers in public hospitals and academics in the universities in China. In this chapter, I also give rationales for the sampling design and sampling strategies in the fieldwork. I explain the necessity of diversity in choosing samples and give the rationales of my sample criteria and sample size. I also show the profiles of the achieved sample, including service users and other stakeholders in the process of health service delivery. Furthermore, I outline the preparation and process of fieldwork for data collection. In the data analysis section, I take the framework approach and thematic analysis to manage and analyse the qualitative data. NVivo 11.0 is used as the analysis tool. Descriptions and explanations are given during the abstraction and interpretation of data. Reliability and validity are also

considered in the data collection and analysis procedures. I discuss ethical issues, including confidentiality and informed consent during data collection. This chapter also addresses the scope and some limitations of the research based on the methodology and practical issues.

Chapter 4 The Political Context of Patient Involvement and Participation

4.1 Introduction

Although practitioners embrace the inclusion of service users in health care on a small scale, a system-wide practice is not promoted in the Chinese health system. This is related to a wider political context that gives meaning to what service users are and how they involve themselves in health service delivery. In this chapter, I concentrate on the analysis of the political context. I will argue that the political context is important to understand the current state of play of patient involvement and participation in China. The political context includes the ideology of health system reforms, political system, relationship between the state and the society, roles of users and mechanisms of participation.

In Section 4.2, I start with the neoliberal ideology rooted in the Chinese health policy-making since 1978 and offer a vivid account of how service users perceive the marketisation of health system reforms and the changing relationship between professionals and patients as a result of neoliberal policies, drawing from patient interviews of the fieldwork in the first stage. In Section 4.3, I elaborate the Chinese political system and 'state-society relations', drawing from the existing literature and empirical evidence from the fieldwork. In doing so, I attempt to provide a detailed understanding of the opportunities and obstacles that collective participation encounters in the health system. As a result of neoliberal health policies, an authoritarian political system and limited development of civil society, service users are created as individualistic consumers in health service delivery. In Section 4.4, I analyse the approach of consumerism and mechanisms of involvement for Chinese service users based on the empirical evidence from the fieldwork in the first stage.

4.2 Neoliberal ideology

In Chapter 2, I outlined the Chinese health system and Chinese contexts (see Sections 2.5). I highlight the role of ideology in health policy, financing and delivery design in China, as it becomes the main driver of the Chinese

health system reforms from the 1950s onwards. Two camps of intellectuals with different ideologies have been consistently debating for a long period: the pro-market camp (the neoliberals) advocates market liberalism; the pro-government camp (the social democrats) supports high government intervention in producing and distributing health services (Duckett, 2011; Duckett and Langer, 2013; Yip and Hsiao, 2015). Yip and Hsiao (2015, pp. 52–53) argue that Chinese health care policies and performance are ‘oscillating’. The two ideological approaches have swayed the impacts on Chinese policy-making during different periods. The pro-government approach dominated from the 1950s to 1978; the pro-market approach was prioritised between 1978 and 2002; the reform plan of the pro-government approach started between 2009 and 2012;¹⁰ the pro-market camp won the debate and China began to introduce private investment in public hospitals from 2013 onwards (see Section 5.2.1).

Overall, China has experienced long-term marketisation and privatisation in health care in recent decades, despite a short change of ideology emerging from 2009 and 2012. In this section, I consider what impacts the ongoing pro-market approach has had on patients and their households. To understand the impact, I ask the following questions: How do you view the current health service delivery? What are your major concerns over health care? Are you happy with health services you have now? How do you like the marketised health system?

4.2.1 The worry of costs

When asked about concerns and satisfaction with health care, ‘costs’ were frequently mentioned by patients and carers. Many said they were worried that they might be charged too much. A major reason, mentioned by respondents, was defensive medicine, taking the form of overprescribing diagnostic tests, procedures and drugs (He, 2014, p. 64). During the interviews, many respondents spoke about distrust and questioned the

¹⁰ In 2009, the Chinese government affirmed the pro-government approach in financing health care and redistributing resources to poorer and rural regions. However, from 2003 to 2008, there has not been a consensus between the two camps as to which approach China would have (Yip and Hsiao, 2015, pp. 56-57).

purposes of tests and examinations. For example, a retired employee from the public sector, who lived in the county, shared his negative experience of having diagnostic tests he did not want. He told me that he tried to ask for more details of services but received rejections.

“They were telling me what those (tests and screenings) were for. Well, this hospital is okay, but the hospital in our county is not good. I was so worried last year in that hospital and I kept asking them what they were for. But they did not tell me.”

(Interview 1106, male, 64, urban employee, Cardiology Department, chronic condition, little education)

A few interviewees hoped that their doctors might ask for agreement before they were prescribed some tests and procedures. A woman, who was retired, said she had to talk to her doctor about tests, as it was expensive. She wanted to see whether she could get rid of unnecessary tests (interview 0406). Nevertheless, a small number of respondents said they understood why doctors required so many tests and screenings. A middle-aged rural dweller said he knew the doctor was trying to exclude possibilities of some diseases (interview 0205).

Another reason that caused the concern of costs was ‘using drug (sales) to support medical care’ (*yiyao yangyi*), which referred to prescribing medicine with higher prices. A respondent who worked in a state enterprise recalled his previous experience in local hospitals. He was often given many medicines, which were expensive but ineffective. He felt stressed about rising costs. He showed me the bills he received that morning. He found that many items were not able to cover by his insurance. He did not trust the hospital.

“The cost is so high—you see—they don’t show clearly what they have charged. It is very confused.”

(Interview 0105, male, 57, urban employee, Cardiology Department, chronic

condition, middle school education)

Another respondent revealed that he seldom bought medicines from hospitals, because they charged too much. He only bought medicines from pharmacies after having a negative experience in the county hospital. He believed that professionals would get payments if they prescribed some specific medicines (interview 1106).

Since the 1980s, health service providers have been generating revenues by over-prescriptions and 'using drug (sales) to support medical care'. This was mainly driven by neoliberal health policies, encouraged by Chinese governments to make health facilities financially independent (Bloom and Gu, 1997, pp. 352-354). Over the past three decades, there has been a decline of government budgets on health care (Duckett, 2011, p. 37). In order to increase income, public hospitals need to introduce high-tech diagnostic tests and imported medicine. There also emerged the prevalence of inappropriate prescribing and over utilisation of hospital services (Duckett et al., 2016, pp. 1005-1008; Li et al., 2012, p. 1076). A patient who caught a cold was commonly prescribed many tests, antibiotics and infusions, as well as a variety of medicines, instead of being given advice of good rest and sufficient water. Consequently, service users had to pay for the services out of pocket, although most of the treatments were unnecessary or even harmful.

4.2.2 Inequalities in access to health care

Although China has established a nationwide health insurance scheme since 2009, the coverage is limited and shallow (Zhang et al., 2017, p. 11). The majority of the Chinese population still need to pay out of pocket for many items beyond the coverage range. Big differences of insurance coverage exist among two categories of service users: UEBMI for urban employees and retirees who work/worked in formal sectors;¹¹ RBMI for unemployed and self-employed urban residents and rural dwellers. The first category

¹¹ It refers to state-owned enterprises and the public sector.

distinguishes between people working for the public sector and people working for the general industries. The coverage range of employees in the public sector is about 90% and above, while the range of other UEBMI users is between 70% and 90%, depending on how much the employers and employees pay and share the portion. However, the coverage range of RBMI is much smaller than UEBMI. A RBMI user who visits a city hospital for common disease may only get around 50% reimbursement for inpatient services.¹²

The proportion of reimbursement is based on the level of visited hospitals. Policies are designed to incentivize people to visit primary care facilities by increasing the reimbursement rates for primary care (General Office of State Council, 2015c). In China, community health centres and township health centres are main bodies of primary care provision (Meng, 2015, p. 139). Township health care centres and village clinics are often in partnership with RBMI. If a rural dweller visits contracted hospitals, the reimbursement rate would be around 90%, much higher than in city hospitals.¹³ For UEBMI users, the reimbursed rates are higher, but still dependent on where is visited. Interviewees confirm this. A middle-aged urban employee who were having treatment for breast cancer said her insurance could cover 85% in the city hospital (interview 1009). Another retired government employee who worked in the county government told me that he would be covered 90% if he had treatment in the county hospital. But he chose the city hospital and the coverage decreased to 80% (interview 1106). A 53-year-old rural dweller who visited the city hospital for coronary heart disease was only covered 50% by his insurance, but the coverage would increase to 70% if he visited the county hospital in his neighbourhood (interview 1107).

¹² The reimbursement fluctuates based on the disease-type, inpatient/outpatient services and medicine. Since 2012, China has launched a Critical Illness Insurance Scheme. The reimbursement for critical diseases, regardless of insurance type, can reach over 70%, such as cancer, coronary heart disease and uremia. But for most diseases, the reimbursement proportion for RBMI users is less than 70%. Costs also depend on type of medicine: only medicine in the list of the Health Insurance Directory is covered. Reimbursement rates of inpatient services are higher than outpatient services. The calculation of costs also varies from user to user, depending on their health insurance condition, hospitals, services and cities (interview 18, see Appendix 6).

¹³ If the rural dweller visits the county hospital in the region, the proportion would decrease from 90% to 75%. If he/she visits city hospitals, the insurance would only cover between 60% and 65% (interview 18).

Although the hierarchical reimbursement system is established to reduce the use of hospital services at higher tiers, limited use of primary and secondary health services in the neighbourhoods still exists (Zhang, et al., 2017, pp. 16-17). This is mainly due to huge gaps in the health resources among various tiers of health services; i.e. village clinics, township and county hospitals have health facilities with limited functions, poor human resources and poor service quality (Pan, et al., 2015, p. 151). Consequently, hospital services at higher tiers are overused.

Overall, inequality in health care exists not only in the provision of a safety net, but an imbalanced distribution of health resources among rural and urban areas. This is contrary to the fact that more vulnerable populations have higher demand for health services, such as rural dwellers, unemployed urban residents and migrant workers. Many rural families go bankrupt due to the escalation of out-of-pocket spending in health care. In the interviews, respondents frequently mentioned 'family burden', which meant that patients and their families had to pay a large sum of money if they had major diseases. The 73-year-old urban employee who worked in an industry said he has spent about 14,270 pounds on the treatments of coronary heart disease for the past 20 years, although his insurance covered 80% (interview 1204). A female interviewee told me that she was diagnosed with breast cancer in the county hospital, but she chose to have treatment in the city hospital. She said it would be a big problem if she had insufficient money for treatment, as insurance covered less for this choice (interview 0603). For many rural residents, the diagnosis of cancer had a dramatic effect on their life. It also meant that their family had to share the costs. A woman living in a rural village said she asked her doctor to remove some treatment programmes because she could only get 50% reimbursement from her insurance (interview 1303).

4.2.3 Perceptions of marketisation

Many interviewees were dissatisfied with the marketisation in the health system. The majority of respondents claimed that they were more in favour of the planned health system before 1978, when they compared what they had now. For example, a 52-year-old breadwinner, who had been diagnosed

with coronary heart disease for six years, complained about health services, especially the unequal access to health care.

“It used to be a free health service in the planned economy. But in the marketised health system, you can afford the service if you have money. If you are poor, you can’t afford it. The health insurance can only cover partial expenses. It is too difficult for me as I have old parents and a young child to support.”

(Interview 0102, male, 52, urban employee, Cardiology Department, chronic condition, high school education)

Another respondent also talked about adverse effects of marketisation. He suggested that governments should take responsibilities for resolving problems of inequality.

“It is too fast for the marketisation. The ‘grassroots’ believe that it is better to have a large government. This is because many people are quite poor, such as the retired, the workers and the technicians, although our country is developing quickly. In the marketised economy, some people are rich and can afford health services, but the majority of people are poor and cannot afford it.”

(Interview 0104, male, 65, urban employee, Cardiology Department, chronic condition, well-educated)

Costs were the main complaint, most of which came from patients with chronic conditions. An old woman recalled health care in the planned system and compared to what it was like now. She had negative views of marketisation of health care. She mentioned high out-of-pocket expenses.

“It was a very good time, as people were kind-hearted. Services were free. But now people are mean. If you have no money, you can’t sustain your spending on health services, especially for patients with chronic disease. We

have to have medicine every day and sometimes stay in the hospital for days.”

(Interview 0203, female, 86, urban employee, Cardiology Department, chronic condition, little education)

A small number of patients recognised the advantages of the current health system, as they believed a marketised system brought more advanced medical techniques and facilities.

“Well, it is quite difficult to say if it is that bad. But we have choices. The technology is far better than the planned economy, such as the angiography and vascular stents. But before that, it was just medicine treatments if you have heart disease. We did not have high technology.”

(Interview 0202, male, 54, urban employee, Cardiology Department, chronic condition, high school education)

Interestingly, some respondents refused to make comments. For example, a retired high school teacher refused to make comments on marketisation, as she felt it was relevant to politics.

“I think I am not eligible to comment on such big issues in our country.”

(Interview 0304, female, 67, urban employee, Cardiology Department, chronic condition, well-educated)

4.2.4 Professional-patient relationship

Due to the rising costs and inequality of health care, the relationship between professionals and patients becomes increasingly strained by tension and violence (Zhang and Sleeboom-Faulkner, 2011). Many interviewees expected a good outcome, as they claimed they spent a lot of money on their treatment. A majority felt the main reason of the terrible relationship was the lack of communication. Most patients wanted to obtain more information from professionals. This was particularly the case in city hospitals, compared to

county hospitals. For example, a woman with acute appendicitis in Hospital 2 said she was unhappy with the engagement with professionals. She repeatedly mentioned how poor the communication was that she had with her doctors, when she wanted to know more about her condition and further treatment. She felt services were terrible and expensive.

“My doctor rarely talks with me, although I really need it. I can meet him every day, as he needs to see wards. It charges 20 yuan for that. He just came over and asked me no more than three sentences. Then if you want to have a group consultation, you also need to pay 20 yuan... When I was diagnosed with acute appendicitis, my doctor told me: come in one month and we would see if it turns worse. I wanted him to explain the radiography. He explained quickly and left. It was also charged! He also refused to do some examinations for me.”

(Interview 0901, female, 27, urban employee, Gastric and Intestine Department, acute condition, well-educated)

Again, one of the carers, who was the sister of the patient, complained about disengagement in Hospital 1. Rather than costs, she said that the main barrier was the gap of health knowledge.

“I think the doctor should at least explain the condition to us. The patient is really scared and nervous. If the doctor comes to tell her what the problem is, the patient would be quite relaxed. Most of us are the ‘grassroot’ and we know little about health care, nor do we understand medical terms... For example, my sister just did a CT, and the test result was there. We would like to see the report as we doubt it may be the pulmonary vascular thrombosis. We searched online that there were three levels of vascular thrombosis. But nobody explained to us in the hospital.”

(Patient's sister, interview 0304, female, Cardiology Department, chronic condition)

High costs were the main reason for the poor relationship in the county

hospital. Health managers and professionals confirmed this issue. A manager in the county hospital thought it was unfair for patients, but she said hospitals had to survive.

“The relationship is very nervous now. The phenomenon has just emerged after the marketised reforms since 1978. The relationship is unequal, driven by economic incentives. The input of the public budget is so little in the health sector that hospitals and doctors are busy with making money and making a living themselves. As a result, patients have to spend more money on health care even though they are the disadvantaged. However, we really have our own difficulties as a health organisation.”

(Interview 14, Case 3)

Health professionals in the county hospital had similar opinions. Some perceived that service users acted like consumers, rather than patients.

“Patients think they are consumers and they want to be cured. But you know, most diseases can’t be cured.”

(Interview 5, physician, Department of Endocrinology, Case 3)

Overall, doctors had to increase the quantity of consultation and therapy, rather than improve the quality of services. Sun and Zhang (2010, p. 60) revealed in a survey that the average length of the consultation in China was 6.34 minutes, which was much shorter than the standard required by the WHO (15 minutes). This problem was also reflected in a nationwide online poll in the ‘Dingxiangyuan Forum’ in 2016: 43% and 34% respondents, respectively, believed that the relationship was ‘very nervous’ and ‘quite nervous’. Only 21% and 2% thought it was ‘ordinary’ and ‘well’.¹⁴ The poll also showed that 54% of respondents believed the relationship would be ‘worse’ in the near future. Regarding the causes, around 84% of respondents believed that it was due to ‘the health system’. More specific reasons were

¹⁴ ‘Dingxiangyuan’ is a well-known online forum of medical sciences.

given from professionals and patients. For the professionals, 90% of respondents attributed it to 'the lack of communication'. For the patients, 94% of respondents believed that 'distrust in health professionals' caused the strained relationship (Investigator of Dingxiang, 2016).

The failure of the professional-patient relationship was related to the neoliberal ideology in the health system reforms, which affected people's views of health care and their roles in the relationship. Service users sought better outcomes and quality if they paid a lot for their health care. Neoliberal policies, including profit-seeking behaviours, unaffordable access and inequalities in health care, deteriorated the reciprocal relationship between professionals and patients.

To tackle problems stemming from marketisation, the Chinese governments have carried out policies to control the out-of-pocket expenses and improve access to health care, hoping to ease the discontent of the general public (Yip et al., 2012, p. 833). However, some policies seemed to be ineffective. Many of the interviewed professionals generally ascribed it to 'the system', as they felt it often conflicted with demands of service users. For example, a surgeon in the city hospital had a patient who was unwilling to leave the hospital, although he was asked to leave due to the excessive expenses.

"The biggest barrier is the insurance system. Health authorities require us to control the costs within the range of insurance, otherwise we would lose our bonus. This is really difficult, as we often meet patients who are not willing to leave hospital. We have to ask them to leave, as we need to control the cost. See, it is the conflict and patients are not happy with it."

(Interview 8, surgeon, Department of Breast Surgery, Case 1)

Another professional complained about the restrictions of prescribing pharmaceutical products within the essential medicines list, as some were not very effective for treatments.

“I believe the root is policies, such as health insurance policies. Patients do not accept medicines beyond reimbursement, as they need to pay extra money. But for doctors, we use medicines which we think are effective. So problems shift to us. That’s why the relationship is so bad.”

(Interview 6, surgeon, Emergency Department, Case 2)

4.3 Political system and state-society relations

In the last section, I argue that ideology is a key factor in affecting perceptions of Chinese service users and their relationships with service providers in health care delivery. In this section, I analyse another political context: the political system and state-society relations. This offers a better understanding of the wider context, how the Chinese political system and state-society relations affect roles of service users, and how service users interact with the state in China.

4.3.1 Political system

There is a plethora of theoretical literature, which explains the Chinese political system. Concepts, such as totalitarianism, the bureaucratic politics model, informal politics, the pluralist politics model, fragmented authoritarianism, are described in detail. These theories and models reflect patterns of the Chinese political system in different periods. The totalitarian model was popular in studying the political system from 1949 to the 1970s with ‘a monopoly control over every aspect of the society, a hierarchically organised one-party system and a centrally planned economy’ (Curtis, 1979, pp. 7–9). But it receives critiques that the model is not applicable to China from the 1980s onwards, when China starts to change substantially by reforms in the post-Mao period (Guo, 2013, p. 12). Fragmented authoritarianism or soft authoritarianism is a well-known theoretical model and offers an alternative for explaining China’s political system after 1978. Lieberthal et al. (1992) uses this model to describe weakening central control, decentralised resources and expanding space for the society below the very peak of the system. But the model fails to explain the changes and forces that take place in the 1990s and onward (see Guo, 2013, p. 19). Pluralist

politics, focusing on subnational governments and the relationship between central and local governments, uses 'de facto federalism' to describe bargaining, competition and negotiations between central and local levels of the party-state in post-Mao China (Zheng, 2007). Other theoretical models, such as the informal politics model (Dittmer, 1995), the modernisation theory and the bureaucratic politics model, attempt to explain some features of the Chinese political system or political change (see Guo, 2013, pp. 15-16). But none of these theoretical models explain all aspects of the complex system and ongoing changes.

Since Xi Jinping took power in November 2012, the Chinese political system has been undergoing steady changes and political development. 'Consultative Leninism' is used by Tsang (2016) to analyse China's political system under Xi's leadership from 2012 onwards. Tsang (2016) argues that Consultative Leninism is embraced by Xi to reinforce the leadership of the Communist Party by strengthening the capacity to respond to public demands, shape public opinions and build up a strong sense of national pride. The Chinese political system is no longer the Maoist totalitarianism, nor is it possible for China to choose to be a liberal democracy in the near future. However, significant political development has been observed in recent decades, including the capacity of good governance, the institutionalisation of policy-making and a developing space for civil society. This provides opportunities for the growth of citizen participation and a variety of engagement between the state and the citizens. In the following section, I attempt to give an account of how the party-state engages with civil society and how collective participation is developing in the Chinese context.

4.3.2 State-society relations

The relationship between state and society has received much attention during the 1990s when China emerged the dynamics of state-society interaction and 'changes within the state sector and society' (Saich, 2001, p. 206). But the relationship is different from the western context, in that it is neither independent nor stable. To know what the relationship is between state and society in the health sector and how it affects the roles of Chinese

service users, I am going to evaluate concepts and policies, and provide the views of local administrators, academics and an NGO leader.

4.3.2.1 The concept of citizens and civil society

Unlike the sociological understanding of 'citizen' in the western context, which encompasses dimensions of civil, political and social rights (Marshall, 1963), the concept of 'citizen' in China is a legal concept, referring to the citizenship of the People's Republic of China. Citizen rights and responsibilities are defined in the constitution. Other alternatives, such as 'the people', 'the mass' and 'the public' are used widely in Chinese official documents. In the discourse of the Chinese Communist Party (CCP), 'the people' and 'the mass' are interlinked with collectivism, that individuals ought to submit to the state and sacrifice their rights (see Hu, 2013).

In the early 1990s, when social changes took place due to the economic growth and political reforms, Chinese scholars began to shift attention to 'civil society' and 'citizens', for which they borrowed the concepts from the western context. The concept of 'civil society' is once used to depict the emergence of Civil Society Organisations (CSOs) and voluntary groups. However, the scholars soon find such concepts are problematic, as the civil society in the Chinese context is not autonomous or independent. 'The state has continued to retain a great deal of its organisational power and has moved to dominate the space and reorganise the newly-emergent organisations' (Saich, 2001, pp. 205–206). The terms of 'society' and 'socialist civil society' are created to replace 'civil society' in the official language of the CCP, as the definition of 'civil society' was not allowed to be used since 2011 (see Ma, 2015, p. 493). 'State-society' is used to depict the relationship by the Chinese Communist Party, replacing 'the state-civil society' and 'state-citizenry'. The CCP also proposes 'strong state-strong society' to reveal their intentions to strengthen the power of the state and the leadership of the party in governing the society (bid.).

4.3.2.2 The relationship of the state and the society

It seems that the government is cautious in supporting the development of social organisations. In 1989, the central government required that social organisations should register in the Department of Civil Affairs and find a supervisory unit (*danwei*) as their sponsors to oversee their activities (Howell, 2012, p. 162). Starting in 1990s, the Chinese government has encouraged the growth of associations and foundations (Jie, 2006, p. 3). The state also preserves power in the society by establishing and sponsoring new society organisations, known as Government Organised NGOs (GONGOs) (ibid.). Howell (2012, pp. 160-161) classifies four types of organisations emerging in China: ‘organisations that are closely related to the CCP and the government-sponsored organisations such as the Communist Youth League (CYL); more independent organisations with legal status such as professional associations or trade associations; more loosely organised, nonregistered networks and discussion groups; illegal organisations’. For the Chinese government, it is the latter two types of organisations that are highly restricted. Local governments, who are implementing policies, conduct annual examinations of social organisations. An administrator in the Bureau of Civil Affairs at the city level confirms it. I am told that the Bureau of Civil Affairs examines social organisations every March to May.

‘We monitor social organisations carefully. We examine around 1000 social organisations every March to May. We require them to submit a report online and a paper version. The materials include the Party Building, financial conditions and activities. The Party Building is the most important part.’¹⁵ If they are unable to pass the examination or give up twice, we will withdraw their licence. We only ask 5% to make presentations every year.’

(Interview 19, local administrator, 2018)

Nonregistered networks and voluntary groups have mushroomed after the millennium, particularly after the *Wenchuan* earthquake in 2008 (see Howell,

¹⁵ The Party Building is a range of learning and development activities of the CCP in order to improve their leadership in governing the state and the society, as well as refresh themselves, e.g. the anti-corruption campaign.

2012, p. 164). Many grassroots NGOs have played an important role in providing services in many areas; e.g. environment, health and education. Moreover, they actively engage with the state to supervise governmental behaviours and make influence through policy advocacy (see Yang, 2005, p. 46; Duckett, 2008, p. 16). As a result, the Chinese government takes advantage of CSOs, particularly in providing services to marginalised groups (see Duckett, 2008, p. 16). Since 2009, many local governments have started to relax the restrictions of the registration standards and exempt the sponsorship of another administrative unit for some particular types of NGOs (interview 17). In 2013, the State Council allowed four types of NGOs to 'register directly', including business associations, technology organisations, community service organisations and charities (see Lu, 2016). This is echoed by Teets (2014, p. 2), who creates the new model of 'consultative authoritarianism' to denote the new state-society relationship that 'combines the pluralistic aspect of democratic governance with the state control mechanisms prevalent in authoritarian regimes'.

In the health sector, loosely organised and grassroots NGOs have grown rapidly after the SARS outbreak in 2003. Duckett (2008, p. 16) documents that these health-related organisations of particular diseases, such as hepatitis B, tuberculosis and cancer, have provided services including counselling and financial support. Huang (2019, pp. 638-639) outlines three areas that are dedicated to health philanthropy: 'infectious disease prevention and control, especially in the area of HIV/AIDS'; 'access to affordable health care for disadvantaged groups'; 'research and advocacy regarding non-communicable diseases and their risk factors'.

I interviewed a leader of a health NGO called the China-Dolls Centre, working with rare disorder patient groups. The organisation helps patients with rare diseases (mainly Amyotrophic Lateral Sclerosis) to apply for government subsidies. It also helps them contact doctors who promise to conduct discounted surgeries.

'We have had the cooperation with one of the provincial hospitals, as we know the doctor well. We have helped the patients exempt some expenses

of surgery. It depends on the doctors, if there are some who are willing to cut or exempt the costs for patients.'

(Interview 20, leader of China-Dolls Centre, 2017)

While non-profit organisations emerge to provide support for the vulnerable groups, the state has also promoted activities of purchasing services from social organisations since 2013 (General Office of State Council, 2013a). The official decision has affirmed the importance of social organisations in providing public and social services.

'With the increasing demand of public services, some problems exist in many fields, such as poor quality, low efficiency, shortage of supply and imbalance of development. Therefore, there is a great need that the government should improve the function of providing public services, innovating service provision approaches, and motivating the society to make contributions for a more convenient, faster, better quality and a more effective public service system.'(General Office of State Council, 2013a)

In the interview with an administrator in the Bureau of Civil Affairs, I asked her about the motives for purchasing services. It seems that the Chinese government is trying to transform its functions from a service provider to a service supervisor.

'It is because the functions of the government are changing. Social organisations are able to play a substitutable role in many ways. Many services are facing the mass directly. The outcomes are not so good if the government is involved in it. And social organisations are more professional.'

(Interviewee 19, local administrator, 2018)

However, policies have become an instrument for the state to control social organisations. In order to help social organisations grow 'in a right way', different levels of government have set up fiscal grants for specialised

projects. Social organisations are motivated to bid for the projects due to the attractiveness of funding. The intention for doing so, according to the interview, is to constrain and monitor the activities of social organisations and cultivate good ones (interview 19). For instance, the Bureau of Civil Affairs selects and makes a list of quality social organisations every year. The intention is to propose suggestions for other departments who are in need of service purchasing.

'As the registration body of social organisations, we pick up eligible NGO organisations and offer the list to other departments who need to buy services. For example, we select a list of 104 social organisations this year. The 104 social organisations are recommended to other departments. They may become their priorities for purchasing services.'

(Interview 19, local administrator, 2018)

Another aspect of strengthening the control of social organisations, is that the party-state tends to promote grassroots party organisations (*jiceng dangzuzhi*) in social organisations since September 2015, when the Chinese government carried out 'Suggestions of Strengthening the Party Building in Social Organisations (Trial)' (General Office of State Council, 2015b). The intention is to retain the leadership of the party and monitor social organisations carefully. The interviewee, who is an administrator in the Bureau of Civil Affairs at the city level, gives the account that the local authority hopes to steer the development of social organisations.

'The policy objective is to promote the development of social organisations by building party organisations. It is required to establish one if there are more than three party members. If there are not enough, two or more social organisations should co-establish one. We hope to strengthen the administration and lead social organisations in a good way. It is called grassroots party building. And we will evaluate their performance every year, for which party building is the most important component. Afterwards, we classify them into many levels, such as 5A, 4A and 3A.'

(Interview 19, local administrator, 2018)

GONGOs and international NGOs are playing influential roles in policy advocacy; e.g. tobacco control (Huang, 2019, p. 639). Only a small number of grassroots NGOs have attempted to influence policy-making. They might lobby the policy-makers, gain support from the media and contact delegates of the National People's Congress (NPC) and the Chinese People's Political Consultative Conference (CPPCC). But even so, grassroots NGOs find it risky and difficult. The leader of China-Dolls reveals that she and her colleagues are working hard to make their voices heard by policy-makers.

'Well, we are trying to get medicines included in the health insurance schemes. We contacted a journalist to help us. Then we knew that he was forced to resign after a while. We also contacted some delegates to make voice during the 'lianghui' period.¹⁶ But we just contacted a small number of delegates. There is one celebrity who seems to be the head of a medical association. He approves to do that, unless we persuade our members to help them with medical research. But we won't agree, as we don't want them to do so. It might not be good for patients.'

(Interviewee 20, leader of China-Dolls Centre, 2017)

According to Chen et al. (2014, p. 5), 'health has ranked third in non-profit fields, after education and poverty alleviation'. But health-related grassroots NGOs face more obstacles than official and semi-official organisations. The main reason is that grassroots health-related NGOs are struggling to survive due to the lack of funding and resources. Grassroots NGOs often encounter obstacles in obtaining funding, engaging in public fund-raising and recruiting quality professionals. GONGOs, on the contrary, have advantages in accessing funding and resources (Huang, 2019, p. 642). For example, the Chinese Medical Doctor Association (CMDA) is a GONGO, whose members are health professionals all over the country. The Red Cross Society, the largest non-profit organisation in the health sector in China, also has a powerful official background to support health service provision in many fields. Moreover, health authorities highly restrict the development of

¹⁶ 'Lianghui' refers to NPC and CPPCC, which are held every spring.

grassroots NGOs, by treating official and unofficial NGOs unequally. On the one hand, the government restricts registration of grassroots NGOs by setting requirements for non-profit organisations, such as finding a supervisory agency and narrowing the range of services. On the other hand, sponsors of health-related NGOs, health administrative bodies at state and sub-state levels, tend to sponsor official NGOs, rather than grassroots NGOs. Unofficial grassroots NGOs find it difficult to attract attention from the government. According to a leader of the China-Dolls, the organisation is often excluded from the shortlist of purchasing service programs when they bid. She says they lose many opportunities because they have 'no official background', nor do they interest local authorities.

'We are grassroots NGOs and have no official background. It would be much easier if you have a background, like some social work organisations. As a grassroots NGO, it is very difficult... We often bid for their programs regarding purchasing public services but never get it. It was one afternoon that the local government selected who won the bid—obviously it was decided before the bid started. Well, they have official backgrounds. And you cannot monitor it as the process is not transparent at all. The government knows little about us—maybe they know better about the NGOs, which provide services for the elderly and the teenagers. But we bid whenever there are projects, as we want to gain more attention from the government.'

(Interviewee 20, leader of China-Dolls Centre, 2017)

The leader also complains about the difficulties to link patients to the government, as the organisation is not well recognised by the government.

'What we can do is to bridge patient groups and the government. But most of the time it is really difficult. We are trying to encourage patients to make voice for themselves. Now we are trying to build the community to make collective voice.'

(Interviewee 20, leader of China-Dolls Centre, 2017)

Despite the growth of health-related NGOs, they are still not widely recognised by the general public. Rather, people are more likely to be involved in disorganised voluntary groups, particularly on the internet. Negro (2017, p. 211) documents that the internet and social networks have promoted the role of civil society in China, of which Weixin (Weichat) is an example. As a mobile platform, the function of Weixin includes one-to-one or one-to-many messaging with text, voice, file, photo and video. It also supports users to set up group discussions (a maximum of 500 people per group) and share posts with contacts in the 'moments' sections. Thus, communication and voluntary activities take place through Weixin, such as charities and public campaigns, although censorship and monitoring of activities by the government are unavoidable (Negro, 2017, p. 204). According to the interviewees, many patients mention their use of Weixin, as it helps them identify patient groups and receive health information from public accounts (gongzhonghao), but none of them have an idea what health NGOs are.

4.4 Consumerism and mechanisms of participation

Service users in many western health systems have various types of participation, such as voting for policies, voice through system and organisational levels, and choice and exit through the market. However, in the Chinese context, mechanisms of participation are very limited. It is hardly possible to vote for a range of policies in the current political system, nor do various approaches of voice mechanisms exist. Consumer choice seems to be the most popular approach, which is greatly promoted by policy-makers in recent decades. In this section, I specifically analyse how Chinese service users engage in health service delivery and how the relationship between the state and the individual is changing as a result of neoliberal healthcare reforms and limited civil society development.

4.4.1 Choices

4.4.1.1 Choice of providers

The core value of consumerism in the medical encounter is the increase of

patient and user choice. It is believed that user choice empowers individuals to decide who, when and what services are provided in public service delivery (Beusekom et al., 2004, pp. 14-15). This is mainly approached through competition of health facilities that empowers patients as consumers to make the most of information and choices of providers and treatments. Thus, the consumerism approach is believed by the reformers to empower service users effectively. Reformers in many countries also argue that patient and user choice are able to promote efficiency, quality and responsiveness in public service delivery (Fotaki et al., 2008, p. 178).

In China, patients are free to choose health facilities in any regions for health services, although their insurances are contracted with particular health facilities in the neighbourhoods. Normally, the better the health facilities they choose, the more costs they have to pay themselves. Primary care facilities are the first choice for patients if their perceived conditions are not serious. Patients have facilitated access to primary care institutions (i.e. community health centres and village clinics) without long waiting times and transportation costs. Township, county and district hospitals are also economical choices for the general public. I ask respondents in the county hospital why they choose it. Most patients who visit the county hospital are rural residents. Frequent responses include 'convenience' and 'contracted hospital of health insurance'.

However, patients may make use of choices under specific circumstances. In the city hospitals, respondents give a variety of reasons why they choose service providers. I am told that service users are motivated to make choices when the conditions turn serious or when the services in their county or town are poor. They may change to better health facilities which are good at specific areas or enjoy a good reputation in the region. For instance, a 67-year-old woman, who has had coronary heart disease for 5 years, told me that she chose Hospital 1 because the clinical department was very good at coronary heart disease. Her family came from a county where the hospital was not good enough. She also mentioned her professional, whom was a well-known physician.

'The cardiology department is the best in the region—that's why we come. We are from Sishui County, but the hospital in our county is not as good as this one. I choose Dr. X once I come. I am accepted very soon.'

(Interview 0304, female, 67, urban employee, Cardiology Department, chronic condition, well-educated)

Another patient, who was 74 years old with the diagnosis of coronary heart disease for 30 years, said he chose the city hospital because the treatments were more advanced than in the county hospital.

'The hospital here can resolve the problem. The doctor is able to place the stents. But in the county hospital, they cannot do it.'

(Interview 0404, male, 74, urban employee, Cardiology Department, chronic condition, high school education)

Some other respondents choose service providers by quality of care. A 57-year-old woman said her family chose the hospital because her children had to work in the daytime.

'The service is really good. My children cannot take care of me in the daytime, as they need to work. The staff looks after me very well.'

(Interview 0503, female, 57, rural resident, Cardiology Department, chronic condition, middle school education)

Service users who live in the city have more choices for higher levels of health facilities. For example, respondents mentioned that they often compared services and costs between the two city hospitals and made a choice.

'The hospital is charged less than the People's Hospital.'

(Interview 0502, male, 74, urban employee, Cardiology Department, chronic condition, high school education)

Some choose the providers that they are familiar with. For example, an 88-year-old urban employee said he had all treatments in Hospital 1 for 10 years since he was diagnosed with coronary heart disease. He claimed that he knew everyone well in the clinical department (interview 0501). Some other respondents made choices based on locality. A 29-year-old man, with the diagnosis of acute gastroenteritis, said he chose the hospital which was close to his place of residence (interview 0702).

Individual characteristics may affect the willingness to make use of choices, such as age, cultural and social capital. It seems that the elderly with poorer cultural or social capital reject making other choices due to the lack of motivation to change and exit. For example, a 62-year-old woman with the diagnosis of breast cancer, who had some primary schooling, told me that she did not consider choosing other hospitals. She only wanted to stay here (interview 0606). Another 68-year-old man with acute conditions, who did not have much cultural capital and social networks, also said that he never considered changing hospitals. He said he would talk to staff when there was something wrong (interview 0902).

4.4.1.2 Choice of treatments

While patients have a variety of responses about making choices of providers, a majority of respondents express their desire for more information from the professionals when they make choices for treatment. Most respondents revealed that their information was not sufficient to make choices. For example, a 65-year-old man who has been diagnosed with Myocardia Infarction (MI) for three months said he was very willing to receive more information from various sources, including professionals and other people (interview 0104).

However, when it comes to choices of treatment, some respondents express

their desire to be more active in the decision-making process, when they recall their actual involvement in making choices. Not everyone wants the responsibility for making choices about their treatments, although they want more information. Two considerations are taken as high priorities for making choices: expected outcome and costs. Some patients reveal their eagerness to know about some treatments that 'cost less but have better outcomes'.

4.4.1.3 Choice of information

According to neo-classical theories, information is crucial for people before they make choices. The neoliberal theorists assume that consumers have complete information and make the rational decisions based on the use of information. 'Choice without information is not real choice' (Gabriel and Lang, 2006, p. 26). In the health sector, service users would select and use the information of hospital performance for choosing providers which is disclosed by service providers. They would exercise their right of exit or create themselves as empowered consumers, which promotes the improvement or closing down of services (Fotaki, 2013, p. 121).

In the Chinese context, however, hospital performance data is not always available to the general public, nor do ordinary service users use the published information. Most people make their choices given the information they get from their health professionals, carers or other social networks. For example, people who go to the primary or secondary health facilities might change their providers on the basis of the suggestions of health professionals. A 40-year-old woman who has been diagnosed with breast cancer for three years said that she was recommended to go to the city hospital by the doctor in the county hospital when he found something was not good (interview 0601).

Those who choose providers based on reputation tend to obtain information from other people (e.g. spouse, siblings, relatives, neighbours, etc.) when they make comparisons among providers. For example, a 57-year-old woman from a rural neighbourhood, who only had some primary schooling,

told me that her relatives recommended the hospital to her, when she found she had breast cancer one month ago (interview 0805). Her relatives told her that their experiences in the hospital were positive. She then made the choice to visit Hospital 2. Another 63-year-old woman with coronary heart disease, who was a retired worker, told me that she learnt from others that facilities in Hospital 2 was very advanced and professionals were well-trained (interview 1103). She then made the choice.

In terms of choices of treatments, many people show that they collect general facts to help with choices of treatment, such as consultation, publications and the internet. A 46-year-old woman who was a computer engineer said she used the internet to understand results of tests and medications (interview 1009). Still many respondents said they got information based on personal experience, such as accounts from other patients, regardless of illness or treatments. A 62-year-old woman with breast cancer from a rural village, who was almost illiterate, told me that she was not the only one who had the disease around her, and she knew a lot from other patients, such as mastectomy and chemotherapy (interview 0606).

4.4.2 Mechanisms of participation: choice, exit or voice

While the neoliberals promote the exercise of consumer rights of choice and exit, service users in China demonstrate a variety of responses. In the fieldwork, I propose the following question to the respondents: What would you do if you are not happy with the health services in the hospital?

According to the analysis, there are a variety of reported mechanisms of participation: voice at the micro-level of service delivery, voice at the higher level of health system, exit, and passive strategies (i.e. doing nothing). Munro (2013, p.4) distinguishes universalistic strategies (i.e. making a formal complaint or change of providers) from particularistic ones (i.e. illegal or semi-legal strategies). He observes illegal and semi-legal proactive strategies for getting health care in the Chinese context, such as paying a bribe and using connections (Munro, 2013, p. 4). In this study, I only consider legal strategies. The first reason is that illegal or semi-legal strategies are not

really observed in the process of fieldwork, except for using personal networks. No particular evidence of 'hongbao' (paying a bribe) and 'yinao' (medical disputes) has emerged in the process of data collection. As the behaviours of 'hongbao' and 'yinao' are forbidden in the policies and regulations in recent years¹⁷, it might be due to the sensitivity of the topic in the fieldwork that I don't obtain any data relevant to this. The use of personal networks is asked in the social context (social capital) to understand how patients and families access health resources and seek support (see Wellman et al., 2002, pp. 223-235). I distinguish support through personal networks from seeking advantage over others through known connections in the system. In other words, patients and their families may possibly use personal networks as a social resource for information and support. Overall, these might explain why the reported mechanisms of participation only demonstrate how respondents seek to exert influences on health care in a legal approach. Secondly, the study is not intended to look at users' attitudes towards unethical practices in China. Rather, it aims to explore how patients and their family wish to use ethical and legal strategies in health care, when they are not happy with services. The study aims to explore the possibility of involving patients and families with institutional arrangements and promote ethical practices in health care delivery. For this reason, I do not consider illegal and semi-legal aspects of proactive strategies.

Overall, there are 82 interview respondents in the first stage of fieldwork. The majority of respondents claim that they are happy with services. For example, a 52-year-old man with acute conditions said he was very satisfied with everything in Hospital 3. He never thought of changing or making complaints (interview 1403). A 46-year-old woman with breast cancer in Hospital 2 also said everything was going all right with the services and there was nothing to make her unhappy (interview 1009).

More than half of the respondents give priority to using voice for a change at the micro-level of service delivery; i.e. talking to health professionals. Some of them who prefer voice in the health system object to other strategies, such

¹⁷ See '*Strengthening ethics of health care industry with nine forbidden behaviours*' (Jiaqiang yiliaoweisheng hangyejianshe 'jiubuzhun') (NHFPC, 2013).

as making complaints to health boards, or exit. This group of people is mainly the elderly and the less educated people. A 67-year-old woman with coronary heart disease said she did not want to make complaints to health authorities, as it was not helpful to her treatment (interview 0304). A 31-year-old woman with breast cancer from a rural village, who had some middle school education, told me that she wanted to be well treated and she would not consider changing to another hospital, as it was useless. She only wanted to talk to the professionals if there was something wrong (interview 0603). Another 46-year-old woman from the rural area, who also had some middle school education, believed that she was the 'grassroot' who cannot do anything, except for talking to professionals. She said it was impossible for the grassroots to win a lawsuit against the hospital, if there were any disputes (interview 0609).

The second frequent response is to make complaints to higher levels of the health system, such as hospital boards and health authorities. Most respondents regard it as an option second to using voice with professionals, as they only feel it necessary if they are very unsatisfied or some accidents happen. For example, a rural resident who had acute conditions said he would only make complaints to health authorities if he was not satisfied with services.

'I would make complaints to relevant departments only if I am very angry with the services. I think the hospital service would be improved by doing so.'

(Interview 0301, 63, male, rural resident, acute disease, Emergency Department, primary school)

Another respondent, who was a retired worker in a state enterprise, said that he considered talking to the board or local health authorities.

'I would like to discuss with the hospital board and give them some suggestions. If there is a medical malpractice, I would consider making complaints to health authorities.'

(Interview 0505, 70, male, urban employee, chronic disease, Cardiology Department, middle school education)

Only two respondents would exit prior to other approaches. Most people who mention exit also regard it as the second or third option, when the treatment outcomes turn bad, or the communication is ineffective. A 60-year-old woman who was a rural dweller said that she would change hospital if the treatment outcome was not good. But she preferred to talk with professionals.

'I would talk with professionals first. If the operation outcome is not good, I would change the hospital. I have not considered to make complaints yet.'

(Interview 1303, 60, female, rural resident, breast cancer, high school education)

It was the same with a 68-year-old retired worker, with the diagnosis of coronary heart disease. He mentioned that he would change hospitals if the treatment outcome was bad, as he did not want to waste time (interview 1104).

Interestingly, some respondents refuse to give an answer. Some are unwilling to talk about it as they are in the hospital. They feel sensitive to mention 'complaints' and 'exit'. Some believe that they have not much to complain about because they know little (interview 0201 and 0404). Some respondents told me that they were afraid of being treated badly by professionals, if they said something negative about them (interview 0303 and 1305).

4.4.3 Consumerism and its problems

4.4.3.1 Choice and equality

Consumerism in the neoliberal context has promoted active choice in individual decision-making and among service providers. Compared to the

paternalist relationship in the past, it leads to a more equal provider-user relationship in health care delivery, as service users have more rights of choice and access to information. Although some research reveal that patients as consumers are empowered with more autonomy and control over health care resources (Fotaki, 2011, pp. 933-934), it seems that it has resulted in an adverse effect on equality when the relatively disadvantaged groups are not able to access information and make use of choices over treatments and providers. In the Chinese context, which is depicted as 'the government controlled market' by Fotaki (2011, p. 946), the better-off take advantage of choice and exit strategies. This is because they are better at accessing information and mobilising to another locality. In contrast, the elderly, the poor and the less educated may find it difficult to access and use information and this leads to little control over choices. For example, most RBMI users are less educated with a lower socioeconomic status. It looks like they have various choices of providers, but their choices are quite limited, as they are more likely to choose the contracted facilities due to spending less money. Meanwhile, many of them also tend to leave decisions to their doctors due to their low cognitive level in health care.

Therefore, albeit the benefits consumer choices have brought in the Chinese context, such as individual autonomy, more rights and greater control over resources, the issue of inequality is serious. In a sense, the advantaged population are given extra privilege through consumer choices rather than this being open to vulnerable groups. The poor, the less educated and the elderly have little control over resources and are not mobilised to exercise choice and exit, leading to the phenomenon of 'difficult and expensive to see the doctor' (*kanbingnan and kanbinggui*) in China.

4.4.3.2 Do patients want choice?

Although neoliberals believe that choice is the best approach to health service delivery, service users, especially patients, do not really want choices in many circumstances. Evidence in the fieldwork shows that the majority of patients prefer voice rather than choice when they experience dissatisfaction with services. Many respondents are keener on making voice at the micro-

level of service delivery, rather than higher levels of the health system, unless complaints to health professionals are ineffective. Some would make complaints at the organisational and system levels; i.e. health boards and authorities. Very rarely they are motivated to exit, only if they feel they have to choose another provider. In terms of treatment options, most respondents prefer more information with fewer choices.

One of the reasons of unwanted choice can be attributed to the nature of health care; i.e. patients are emotional when they encounter problems in relation to their health. Patients are less likely to make rational choices, as they are anxious and eager to be cured (see Jost, 2007, p. 93-94). Some respondents express their unwillingness to engage with organisations and change to other service providers. Moreover, patients often show higher expectations over service providers and treatments they choose, even though choices sometimes are not 'wise'. For example, a respondent who chose medications for coronary heart disease expressed her expectations of being cured, although her doctor suggested placing two stents within the vascular (interview 0304). Many patients also mentioned that they regretted their decisions under some circumstances, especially when the seriousness of conditions increased or they had little patient experience or knowledge, which echoed Thompson's findings (2007). While consumer choice promotes shopping around in the market of health care, it seems to overlook the fact that health care is not a commodity; people are less likely to opt and consume health care even though they seem to have choices. Emotional patients are afraid of taking responsibility for making decisions, although they are entitled to exercise rights of choice.

4.5 Summary of findings

Given the extensive range of views in the chapter, it is not difficult to unfold the political context of patient involvement and participation in China. This chapter focuses on the political aspect of the issue, which provides a fuller picture of what the wider environment looks like.

In the study I identify that the interactions of patient and health professionals

in daily life are deeply influenced by political factors; i.e. ideology of health system reforms; the political system; relationship between the state and the society; roles of service users and mechanisms of participation. I also examine how the professional-patient relationship is changing after the pro-market policy was implemented since the 1980s. These factors, including ideology, political system, state-society relations and the consumerist approach are not independent, but correlated. For example, consumerism is a core element of a neoliberal approach; state-society relation, to some extent, is affected by the political system. In this chapter, the factors are discussed in detail as to how they make an influence on Chinese patient involvement and participation, both from the historical perspective and the empirical views of current Chinese health service users.

While there is a range of literature discussing the pro-market approach of health policy-making in China, rare research offers a narrative understanding of how service users view the changes in the health system and the impacts on service experience. According to the empirical evidence, it has had a negative influence on the general public. Health service users complain about an increase of out-of-pocket expenses and are suspicious of prescriptions from professionals. The disadvantaged, particularly the rural dwellers and urban unemployed who have the poorest health insurance scheme (i.e. RBMI), are suffering from the differentiation of health insurance systems, with its differential proportions of insurance reimbursement, resulting in serious inequality in access to health services. In the interviews, service users provide a variety of viewpoints of the ongoing marketised health system reforms, when they compare it with the planned health system before 1978. In general, users who are more in favour of a planned health system, express their dissatisfaction with the pro-market approach. In particular, patients with chronic disease are the most unhappy ones, as they spend much more than other patients. There are two kinds of values regarding health care delivery: some respondents who are elderly and with RBMI believe that the provision of health care should be equitable to the general public, while some young people and urban employees believe that individuals should share more responsibilities of health care. Moreover, given the escalation of health care costs, the professional-patient relationship has been under stress for a long time, which is regarded as one

of the most serious social issues in China (He, 2014, p. 66). Many service users express their distrust in doctors and dissatisfaction with service quality, as many spend a lot of money on health services.

There is some dedicated work on the political system and civil society development in China, such as by Guo (2013), Saich (2001), Howell (2012) and Yu and Guo (2012). In Section 4.3, I combine literature, policy documents and empirical evidence to describe how the Chinese political system operates and the relationship between governments and social organisations. Evidence reflects the fact that health non-government organisations in China have little space to develop. On the one hand, the central and local governments set restrictions on the registrations of grassroots NGOs and monitor their activities strictly. Although the governments are keen on purchasing public services in some particular fields, most of the projects have been offered to those who are connected with the governments. As revealed by some research, the party-state has altered political participation in the domains of administrative decision-making, the economy, the judiciary and a nascent civil society (He and Warren, 2011, p. 275). Therefore, citizen participation in the health sector only emerges in the forms of 'party approved NGOs and media watchdogs' in the domain of civil society (ibid.). On the other hand, the limited development of civil society in the health sector might be attributed to the existence of powerful professional associations, as they have more resources compared to grassroots NGOs. Only a very small number of grassroots NGOs find space for service provision and most of them provide services for vulnerable populations, which the governments find hard to reach. In terms of policy advocacy, health NGOs have a long way to go as they are in the careful control of the governments. There is no institutionalised citizen participation in the Chinese health sector. Grassroot civil society organisations have many obstacles to survive and develop under the control of the party-state.

As a result of the neoliberal approach, patients as consumers exercise their rights of choice and exit in the health market, which becomes the main channel for involvement and participation in China. Despite the abundant evidence of choice for treatment decision-making at the clinical level, only a

few scholarly works have explored choice of service providers and how patients use information to make choices in the Chinese context. Therefore, I offer a more sophisticated account of what sources of information service users collect, and how they make use of choice of providers. The evidence shows that patients and their family members are motivated to change providers when the illness turns worse or current services are poor. Various reasons for making a choice of provider include reputation, locality, surroundings, costs. Yet, there are factors that constrain choices: the consideration of costs confines service users within a certain geographic region; e.g. local county and township hospitals are contracted health facilities with RBMI users. Other factors including age, cultural and social capital may discourage service users from making use of choice due to the limitation of resources available. Unlike consumers in the western neoliberal contexts, Chinese service users, according to the interviews, are not used to gathering information from performance data released by service providers. Rather, the channels for choosing information are more informal and irrational, such as their social networks or from their General Practitioners, who are not necessarily trained or interested in assessing performance data. Three main mechanisms of participation are found from the evidence: voice through the micro-level interactions with health professionals and through organisational and administrative levels (i.e. hospital management boards or health authorities); consumer choice and exit. The mechanisms reflect nothing of citizen participation in civil society space and reveal a popularity of informal mechanisms in economic and administrative domains. While the majority of respondents are keener on using voice with their professionals, some express that they consider exit and make use of consumer choices. Only very few desires expressing voice through higher levels of the health system. Nevertheless, we have been able to see a variety of viewpoints and experience of patient involvement and participation, including some who are opposed to any forms of involvement.

By the end of Section 4.4, two problems of consumerism have been discussed in terms of equality and choice itself in health care. An adverse effect is found that the disadvantaged groups in China do not actually benefit from consumer choices as they have little control over resources, such as limited access to health care and inability to use information. Meanwhile, the

resistance to choice by emotional patients reveals the nature of health care, which is distant from the context of rational choices. Despite the popularity of consumer choices in health care, choices are undesirable under many circumstances.

4.6 Concluding remarks

In this chapter, I particularly look at the political context of patient involvement and participation, which is different from developed democracies. The focus on political aspects enables a better understanding of how the political context gives meaning to involvement. The unique political context in China facilitates the individual approach of involvement, as a result of neoliberal marketisation, political system, little civil society space and consumer choices. The collective approach, for instance, through voluntary groups, has been rarely found in the health sector. Seldom does participation take place at higher levels of the health system, such as making influences on policy-making and local health governance. Therefore, the political context, to some extent, has restricted the approaches of patient involvement and participation in health care. Meanwhile, a negative influence has been identified in the professional-patient relationship, as the marketisation and profit-seeking behaviours erode the trust between the two sides. However, modern health care today, especially the management of chronic illness, requires 'a partnership of equals between patients and professionals' (Hunter, 2004, p. 52), confirmed by many service users in the interviews.

A limitation of the chapter is a lack of breadth of the sampling for civil society organisations. It may provide more varied viewpoints of state-society relations and civil society development in the health sector if I sample more CSOs. But this is due to limited access to CSOs in the health sector. There is also a need for a quantitative approach to see the distribution of viewpoints in the current health system, use of choice and information, and mechanisms of involvement, as it enables us to explore how different groups perceive and understand the political context.

Chapter 5 The Policy and Institutional Contexts of Patient Involvement and Participation

5.1 Introduction

This chapter provides an extensive analysis of the policy and the institutional contexts of patient involvement in China. I draw upon policy documents and empirical evidence from the fieldwork. In this chapter, I will argue that there is a lack of policy support as a national strategy in the current health system reforms. I will also argue that the heterogeneity of the institutional context in health facilities plays a key role in affecting the practice of patient involvement and participation.

In Section 5.2, I explore three aspects of the policy context: the ongoing health system reforms in recent years; policy-making and implementation of central and local governments; policies of patient involvement and participation in health care. This analysis allows for an understanding of policy contexts revealing that China lacks policy support for patient involvement and participation in the health system.

In Section 5.3, I examine the institutional context that affects the practice of patient involvement and participation, by drawing upon viewpoints of health professionals and health board managers. Some questions regarding understandings and preferences for patient involvement are proposed in the interviews. Afterwards, I compare differences between the institutional context in three local hospitals in the fieldwork. This analysis allows for a further understanding of how the institutional context plays a role in shaping values and the practice of patient involvement on the ground.

5.2 The policy context

To understand the context of patient involvement and participation at the macro level, I look at public policy in the health sector. I first outline health system reforms since 2009 after the marketised health system has caused serious problems, such as inaccessibility, low satisfaction and inequality.

This helps to understand what the Chinese health system is focusing on and why there is little policy support for patient involvement and participation at the state level. Afterwards, I examine the legislation and administration of health policies, which allows for a better understanding of policy-making and implementation within political institutions in the health sector. Then I provide a brief review of current laws and regulations regarding patient rights and involvement. Lastly, interviews with local administrators at the province level also provide evidence to understand the policy gaps in the field.

5.2.1 Health system reforms in China

After a failure of marketisation in health care since the 1980s (Blumenthal and Hsiao, 2005), China launched a new system in 2009. The priorities of the new plan announced in 2009 included five components: the basic medical insurance programmes, a secure medicine supply system, health service delivery, public health service system and public hospital reforms (Süssmuth-Dyckerhoff and Then, 2017, p. 137). The basic medical insurance programmes are designed to expand the coverage of health insurance and increase levels of reimbursement. The medicine supply system ensures the supply of essential medicines and controls prices. The improvement of health service quality focuses on the inefficiency and low satisfaction with health care, resulting from a lack of a primary care system and marketised health service delivery. The provision of public health services aims to increase services to special groups, such as immunisation of children, health management for pregnant women and health education for patients with chronic disease. Public hospital reforms attempt to improve funding mechanisms and control the costs of health care, as well as establish a set of performance indicators for public hospitals.

It is evident that the 2009 health reforms prioritise resolving problems of inaccessibility and inequality. Rural populations who have lost their benefits in the previous marketisation of health reforms would be compensated with a more equal health insurance and accessible service environment. Until the year of 2012, over 95% of the Chinese population had a basic health insurance provided by the Chinese government (Meng et al., 2012, p. 812;

However, the new reforms in 2013 started to promote privatisation in the health sector. For example, the health reform encouraged private investment in health services and an increase of the private share of public hospitals (General Office of State Council, 2013b). In October 2013, the Chinese government announced initiatives for promoting the health service industry, including the expansion of the role of private sectors in health services, as well as health insurance and elderly care (State Council, 2013). In June 2015, the State Council released a notice to promote the involvement of the private sector in many aspects: relaxing restrictions of entering the industry, subsidising private health organisations, allowing physicians to practise freely and establishing a regulation system for private health facilities (General Office of State Council, 2015a). In many ways, reforms since 2013 have emphasised competition and more supply of health services, although reforms between 2009 and 2012 seemed to establish an accessible and equal health system for the population.

Overall, the complex Chinese health system reforms attempted to resolve problems of inefficiency and inaccessibility of service delivery. In the beginning years of the 2009 reforms, patient rights and patient involvement seemed not to be the priority of health reformers. An exception was a recent policy, released in September 2016, which the Regulations of Health Care Quality Administration implemented (National Health Commission of China, 2016). Measures have been taken to establish a system of performance evaluation, for which service quality was one of the most important components. Since 2015, the improvement of health service quality has begun to draw more attention from reformers (Sun et al., 2017, p. 2). Working plans were made to improve quality services continuously. For instance, the working plan (2018-2020) released in 2018, carried out by NHFPC, has clearly set goals to improve patient satisfaction in many aspects (National Health Commission of China, 2018). However, the plan gives priority to resolve problems of resource shortage and inefficiency of service provision, such as introducing appointment systems, developing a telemedicine system, and promoting day surgery. It seems that patient rights and involvement in

health care delivery are not getting enough attention from reformers.

5.2.2 Policy-making and implementation

The policy-making process in the Chinese government system has special contexts. First, beyond the legislation system, Chinese administrative bodies are involved in health legislation and policy-making. This is mainly because most health legislation and policies are either administrative laws or regulations (Meng et al., 2015, p. 4). Laws issued by the legislation system only provide guidance for specific policies and regulations. Unlike the policy process in many developed democracies, the Chinese policy process is not a policy cycle with several stages. Rather, it is more like a black box with complex interactions within political institutions. For instance, agenda setting is approached through institutional political participation, known as NPC and CPPCC, which are held every spring. Representatives of NPC and CPPCC, who are mostly elites in governments and industries, make proposals to the Party. Some proposals may draw the attention of policy makers (i.e. officials in NPC, the State Council and its departments), who play key roles in policy formulation. Investigations (*diaoyan*) and symposiums (*zuotanhui*) are then conducted to gather viewpoints from local authorities, technical experts, the media and the general public (e.g. surveys and public hearings) (interview 16, interview 1)¹⁸. Policy-makers are mainly officials from central government. According to the interviewed academic who is expert in public policy and central-local relations, the attitudes of policy-makers towards proposals and viewpoints are crucial for direction in policy-making (interview 16).

Second, Chinese policy-making involves a range of bureaucratic agencies within a horizontal organisational structure. Various departments in the central government are involved in health policy-making. For instance, the policy-making of basic health insurance schemes in 2009 included MOHRSS, MOF, the Ministry of Civil Affairs (MCA) and NHFPC. The MOHRSS is responsible for making policies of expanding health insurance for urban employees and residents, while the NHFPC is responsible for improving the security net for rural residents (General Office of the State Council, 2009).

¹⁸ The details of interviewees in this chapter is shown in Appendix 6.

Meanwhile, the MCA is in charge of social assistance for the disadvantaged groups. More governmental bodies, such as the National Medical Products Administration (NMPA) and the National Development and Reform Commission (NDRC) are involved in other health reforms, such as the establishment of a medicine list and the control of medicine prices. However, coordination across governmental bodies is difficult, as bureaucratic agencies are acting as stakeholders, which seek benefits and interests at various stages of the policy process (interview 16). Some scholars studying environment policies, identify competing motives and different interests among state institutions in shaping the regulations of non-governmental organisations (see Howell and Duckett, 2019, p. 6). It is also true in the health sector, remarked by Chen Zhu, the former Minister of Health, that institutional benefits have become the obstacle of intersectoral cooperations in policy-making (Zhao, 2017).

Third, local governments mainly play a role in policy implementation, but they also have flexibility for adjusting specific policy goals and autonomy in piloting policies. Although the central government is dominant in legislation and decision-making, local governments at provincial levels are flexible in 'tailoring healthcare to their socio-demographic and fiscal needs' (Süssmuth-Dyckerhoff and Then, 2017, p. 137). For example, the reimbursement of medicine varies from city to city. Service users may be covered by their insurance in one city, but they may pay for their expenses in another city (interview 18). Meanwhile, local governments are able to influence policy-making via policy experiments, which lead to policy diffusion at higher levels (Teets and Hurst, 2014, pp. 8-12). A situation, depicted by Su and Wang (2016, pp. 7-8), is that local governments are motivated to carry out policy innovations when they find opportunities for policy change at state level. In this way, they draw the attention from the top level to show that policies are possible based on the experiences of local pilot projects. However, it is not always happening. In most cases, the central government selects locations for experiments and offers policy guidance. Local governments would provide feedback to the central government in the process of implementation. It then appears that local governments are in compliance with central governments, but local administrators have their own ways to influence policy-making, such as policy innovation and autonomy of adjusting policy goals

(interview 16). This has led to variations in health service delivery at local level.

In general, policy-making and implementation rely more on political elites and institutions. Central government is in control of policy-making despite the difficulty of intersectoral coordination. Complex engagement exists in the political system, with limited influence from local governments and some autonomy of policy implementation.

5.2.3 Policies of patient rights and empowerment

The legislation of patient rights and empowerment can be found in civil laws and health laws, for example, the Law of Practising Physicians, the Medicine Administration Law, the Tort Law, the Regulation of Medical Accident Management (Meng et al., 2015, pp. 17-18). Current policies regarding patient rights and empowerment reinforce the right to information, including information on illness or condition, treatment options and risks, as well as costs of treatments. Some regulations have been carried out to protect patients from medical accidents, including the rights to see and copy medical records, and to know about medical accidents and malpractice (ibid.). Informed consent is required as the essential procedure in medical practice.

Laws and regulations also highlight the rights of family members in the decision-making process. For example, the Law of Practising Physicians requires that physicians should inform patients or family members of their illness or condition, but they should avoid making any negative impact on patients (National People's Congress of China, 1999). The underlying meaning of the law is to protect patients when they are unable to accept negative news psychologically. There is also evidence that professionals and lay carers are not willing to involve patients with newly diagnosed cancer in the treatment decision-making process in the primary stages. Similar regulations can be found in the Regulation of Medical Accident Management, specifying that health professionals should explain the condition, medical treatments, potential risks and alternative treatment schemes, and obtain consent from close family members prior to patients when the conditions are

negative (State Council, 2002).

It is evident that no specific policies in China explicitly mention decision-making in health care delivery, despite the right to information. Laws and regulations protect patients from being involved in health care decisions when information is negative. Instead, family members are given priority for involvement.

5.2.4 Evidence from local administrators

To understand the policy context of patient involvement and participation, I conducted a group interview with two local administrators at the provincial health authority. Due to the inaccessibility of officials in central government, I chose interviewees at the provincial level because provincial governments had more opportunities to be involved in policy-making and more power to make local plans and regulations. I was recommended by a local university in order to gain access, which was a necessary mechanism in China. The two interviewees were health administrators in the provincial health authority.

The interviewees showed negative attitudes towards patient involvement and participation and it was rarely paid attention by policy-makers. While most policies emphasised organisational reforms, little mentioned rights of service users. The interviewees believed that health care was a very professional field and patients and lay carers were incapable to get involved. One respondent commented:

'Some particular patients and their families can engage with doctors in the process. But most people are not able to be involved, as health care is really very professional.'

(Interview 1, local health administrator, 2017)

They also talked about their understanding of involvement and participation:

information and choice. They believed that information was well implemented and choice was the most effective way to exercise rights.

'When you talk about patient rights in China, current laws and regulations are all about informed consent and choice, through which service users can be involved in health service delivery. I think the process of health care is very relevant to right of choice, for example, which hospital to visit, which doctor to see, whether to have an operation or not, how to be treated and what advice to follow.'

(Interview 1, local health administrator, 2017)

When asked about voice, one respondent did not really have an idea what it was. The other respondent said his understanding of voice and participation was more relevant to making complaints and proposing suggestions. He denied any opportunities of having two-way communication between service users and providers, believing that it was difficult to achieve in practice. He explained it as being connected to the shortage of resources in China.

'We are doing well in establishing complaints procedures and involving suggestions and giving feedback. But it is really hard to achieve a two-way communication, as there is a huge gap between demand and supply...I mean resources are very limited. If you want to achieve patient involvement and participation, much more time and effort should be put in. This is likely to happen when resources and demands of services are balanced.'

(Interview 2, local health administrator, 2017)

The first interviewee talked about difficulties to promote patient involvement and participation by policies. He said it may not be applicable to bigger public hospitals, such as hospitals at state and provincial levels.

'It is understandable that patients have a couple of questions to consult with doctors. However, it is very common in big hospitals that a professional

needs to have consultations with more than 100 patients in one morning. Each consultation lasts no more than 10 minutes. Some are less than 5 minutes. It is hardly possible for a doctor to answer every question for a patient.'

(Interview 1, local health administrator, 2017)

According to local administrators, the main reason for giving no priority to patient involvement was the gap between resource (supply) and demand, which hindered quality improvement of health services in the current health system. The other respondent compared the problem with two triangles: the distribution of health resource was an inverted triangle; the distribution of demand was a pyramid (interview 2). Resources were scarce at the bottom level, with a much larger population with poor socioeconomic status. Therefore, professionals at the bottom level had insufficient time to engage with patients.

The interviews with local administrators reflected the fact that there was inadequate understanding of patient involvement and participation. Mechanisms of choice and information were regarded as effective approaches of ensuring patient rights and involvement in health service delivery. There was also evidence that the issue had not been given much attention by policy-makers in China.

5.3 The institutional context

Besides the policy context, the institutional context also plays an important role in affecting people's behaviours and desires for involvement and participation. This is mainly reflected from how engagement takes place in practice and how much involvement front-line practitioners believe patients have. Thus, I explore institutional factors from the perspective of patient involvement in practice, understanding and values of health professionals and health board managers, as well as institutional differences between selected cases.

5.3.1 Promotion of patient involvement in practice

Despite the lack of policy support, the benefits of user input in health care delivery are highly valued by practitioners. In fact, health facilities and professionals in practice embrace patient involvement and participation. 'Patient-centred care', firstly proposed by the MOH in 2005, underlines informed consent, right for choice and a good professional-patient communication (MOH, 2005). Quality monitoring organisations and complaints procedures have been established to improve quality and responsiveness of services as a national campaign.

The most popular practice of ensuring patient rights is informed consent. Informed consent is well promoted at every stage of health care delivery by front-line practitioners. Some clinical departments, particularly those working with chronic diseases, value contributions of service users in improving patient safety. A recent new initiative is the promotion of *Ten Objectives of Patient Safety in 2019*: patients and family members are encouraged to participate in improving patient safety, including information exchange with professionals, facilitation with understanding and choosing treatment options, identification, provision of authentic symptoms and training of safety education (The Chinese Hospital Association, 2019).

However, the practice of patient involvement and participation varies among regions and health facilities. According to the interviewed surgeon in Hospital 2, in some top health facilities, such as tertiary hospitals in developed areas, informed consent and involvement in patient safety are incorporated in their institutional designs (interview 3). However, informed consent is poorly implemented in some county and township hospitals and professionals only inform service users of limited treatment options. Other issues, such as potential risks and adverse effects of treatments are omitted (ibid.).

5.3.2 Understandings and values of patient involvement and participation

5.3.2.1 Viewpoints of health professionals

I interviewed professionals who were working with different types of diseases. I was interested in knowing their understanding and values of patient involvement and participation, roles of family members and current policies, as well as their experiences of engaging with patients regarding patient preferences. I asked: What do you think about patient involvement and participation in health care delivery? Do you involve patients in the decision-making process and how? Do you have a priority to involve patients or lay carers? What do you think of current policies regarding patient rights?

1. Understandings and values of patient involvement and participation

Interviewed professionals seemed to have various understanding of patient involvement and participation. Most respondents linked involvement with the protection of patient rights, as they recognised that health professionals were too powerful. They believed that professionals should involve patients and family members actively. For instance, a physician in the Department of Cardiology believed that involving patients ensured their rights in health care delivery.

'It protects rights of information, choice and life, and make sure patients have the right of health and health service quality.'

(Interview 4, physician, Cardiology Department, Case 1)

All interviewed surgeons agreed that involvement was necessary when they discussed treatment options. A surgeon in the Department of Urinary Surgery believed that involvement should be implemented in the whole process. He greatly valued contributions of patients, including providing specific details of their illness history and symptoms for diagnoses, choosing treatment options and preventing recurrence of diseases (e.g. cancer).

'The more specific details patients provide, the more precise doctors make judgements...We encourage patients to know more information about treatment options. They can ask their doctor friends and search the internet. It helps them make right decisions...It is even more important for patients to be involved in post-treatment follow-ups. If patients do not participate actively, follow-up interviews might be lost. It is important for us to find problems and prevent the recurrence of tumours.'

(Interview 3, surgeon, Department of Urinary Surgery, Case 2)

A physician in the Department of Endocrinology in Hospital 3 had a different view. She said patient involvement was like 'a process of learning health knowledge'. This was mainly due to her daily work with diabetic patients.

'Diabetes is a disease that needs high levels of involvement. As a doctor, I always spend much time teaching my patients everything about diabetes, including diet, fitness, a regular life and medicine use. Then I think they would be able to manage their illness. I spend much time talking with them, and my consultations last from 5 minutes to 1 hour, as I will make sure my patients know everything.'

(Interview 5, physician, Department of Endocrinology, Case 3)

When I asked her if she treated patients in a hierarchical way, she denied it and said she regarded patients as friends, equal to her. She illustrated that the learning process was unlike the relationship of teachers and students. It was more like a 'partnership'—partners for a healthier life.

While most interviewed professionals believed in the importance of involving patients at the clinical level, a notable exception was a professional from the Emergency Department in Hospital 2, who believed that patient involvement and participation was not suitable for emergency treatments.

'It is very important indeed. But it is not suitable for emergency treatments. I

think patient involvement and participation is only applicable to those whose conditions are stable, especially those in-patients. But it is not realistic to talk about it here. We can only ensure informed consent. What's more, it is rare for patients to want to be involved in emergency care.'

(Interview 6, Surgeon, Emergency Department, Case 2)

Professionals sought opinions from patients and family members. This situation was reflected in the interviews with health professionals. Some professionals revealed that they often asked patients and their family members to choose treatment plans, to avoid conflicts caused by cost disputes. This argument came from a physician in the Department of Breast Cancer in Hospital 3, who believed that involvement was 'informed consent'. She explained the procedure as a process of giving recommendations and negotiating costs. Patients and professionals achieved mutual agreements with a most 'economical' plan (interview 7).

2. Experience of preferences over treatments

Although professionals held various viewpoints of patient involvement and participation, interviewees recalled their experiences of the decision-making process as 'highly important'.

Some respondents claimed that they would give every detail of illness and treatment options to patients and family members. Service users were encouraged to obtain various sources of information that were relevant to their illness or condition.

'We will tell them which treatment is better and which is not. But we encourage them to know as much as they can. This helps them to make the most appropriate decisions.'

(Interview 3, surgeon, Department of Urinary Surgery, Case 2)

But a surgeon from the Department of Breast Surgery in Hospital 1 was

critical about the range of information sources. He said it was vital for service users to obtain reliable information, rather than being misled by other sources.

'Internet is the most popular information source. But some of the information is totally misguided and wrong. Patients also ask other patients with similar conditions. Some of them even ask other professionals for a second opinion. When they come over to see me, some patients have wrong information. I really recommend patients are selective in their sources of information.'

(Interview 8, surgeon, Department of Breast Surgery, Case 1)

I collected two kinds of viewpoints from respondents when they talked about decision-making with patients: some professionals insisted on Shared Decision-making (SDM) with patients, while others informed them of the illness and treatment, but made decisions on behalf of patients. It seemed that surgeons tended to favour SDM more, while physicians liked to recommend treatments for patients.

For example, the surgeon from the Department of Urinary Surgery in Hospital 2 told me that he liked SDM. He gave an example of benign tumour treatment.

'If the tumour is benign and no bigger than 4 centimetres, the operation is optional. I would inform patients of the condition and treatment options clearly. But if the tumour is over 4 centimetres, I would suggest an operation. But there are many types of operations, such as traditional surgery, laparoscopic surgery and the updated surgery called minimally invasive surgery. I would talk and discuss with my patients. I encourage them to know the treatment by all means, such as searching the internet and asking for a second opinion. I prefer to respect their choices.'

(Interview 3, surgeon, Department of Urinary Surgery, Case 2)

In contrast, a physician of diabetes in Hospital 3 said she was willing to choose a 'cost-effective' treatment for her patients.

'I always give my patients 4 or 5 treatment schemes and inform them of every detail of each scheme. If they have no idea what to choose, I would tell them the differences and make decisions for them. I would choose a cost-effective plan for my patients. Most of the time, patients would follow my advice. Very few object to it.'

(Interview 5, physician, Department of Endocrinology, Case 3)

A range of factors, mentioned by professionals, is likely to affect patients' preferences over decision-making, such as educational background, costs and side effects. A physician from the Department of Cardiology in Hospital 1 said most patients would follow doctors' advice, but some factors did affect whether they wanted to be involved.

'Most patients tend to follow the suggestions of their doctors. But it is also affected by their educational level and health literacy and some economic considerations. People with a higher education are more likely to follow doctors, and it is the same with people who have a poor educational background. When it comes to economic thoughts, it is more complex. They may follow advice, but in most cases, they may select a cheaper but less effective one.'

(Interview 4, physician, Department of Cardiology, Case 1)

Sometimes, professionals came across patients who had no capacity to make any decisions. In this case, a respondent explained that full information was provided even though decisions had to be made by professionals. He underlined that the professional-patient relationship was lacking much trust in China.

'We should explain everything to the patients, although decisions are finally made by us. Patients should know which option is better and which is not. But in our health system, you know, the doctor will not make decisions for

the patients without giving any information. Only two cases allow it to happen: the patient is a family member of the doctor; the doctor himself is a fool...

(Interview 3, surgeon, Department of Urinary Surgery, Case 2)

A surgeon from the Department of Breast Surgery in Hospital 1 stressed the importance of SDM, even though the relationship was trusty.

'The role of patient is irreplaceable. I really recommend sharing decision-making. But there are some patients who trust doctors and ask me to make decisions. In this case, I need to inform them of everything and give my advice. But I tell them that it's just advice.'

(Interview 8, surgeon, Department of Breast Surgery, Case 1)

3. Priority of involving service users

I asked health professionals to what extent they involved lay carers in the decision-making process, whether and when they had priorities for involving them.

Most professionals believed that family members were as important as patients. A physician from the Department of Endocrinology in Hospital 3 emphasised the lay carers' key role in improving treatment outcomes.

'I think both patients and lay carers are very important. It is difficult to say who is more important. Everyone needs to be involved in treatments of endocrine system diseases. The job for lay carers is to supervise patients in their everyday life, such as taking medicine on time, doing sports and keeping a healthy diet. This is very key for treatment outcomes. And a good outcome is really related to involvement.'

(Interview 5, physician, Department of Endocrinology, Case 3)

However, a surgeon from the Department of Breast Surgery in Hospital 1 thought that it might depend on conditions or disease-type. He believed that patients were more important than lay carers in many cases. But he mentioned a situation when the involvement of lay carers was necessary.

'Tumour is quite special, as many family members are not willing to involve patients in the process. They may choose not to tell them the truth if it is malignant. In this case, patients know little information and most decisions are made by their families.'

(Interview 8, surgeon, Department of Breast Surgery, Case 1)

4. Views of current policies

I asked professionals about their understanding of current policies relevant to patient rights and involvement. All professionals talked about informed consent, as it was the only policy they knew. A surgeon in the Department of Urinary Surgery in Hospital 2 specifically said that there were no special policies except for informed consent.

Informed consent was well promoted in medical practice. One of the interviewees, who was a physician in Hospital 1 argued that informed consent was currently the most important procedure.

'The hospitals carry out rules and regulations based on current laws. Everyone knows informed consent, as we must sign it...Informed consent should be signed in every step, from diagnosis to treatment options.'

(Interview 4, physician, Department of Cardiology, Case 1)

Many interviewed professionals held a negative opinion of informed consent. A physician criticised that in essence, it was like 'shrinking responsibilities' and it was not really effective to improve the professional-patient relationship. She said informed consent implied a distrustful relationship (interview 4).

Another physician argued that the informed consent's objective was the prevention of medical malpractices. She compared it to the past, when informed consent was rarely promoted.

'Informed consent is taken very seriously in the health sector... But in the past, it was not so important. Doctors asked patients if they needed treatments and medications, and everything was through oral agreements. But there have been too many medical malpractices in recent years. The hospitals require doctors to inform patients of treatment measures and obtain their consents with signatures. Adverse effects should be informed in advance.'

(Interview 5, physician, Department of Endocrinology, Hospital 3)

Similarly, a surgeon from the Department of Urinary Surgery in Hospital 2 also believed that informed consent was meant to protect professionals from medical disputes. He also thought it forced professionals to communicate more with patients (interview 3)

However, a surgeon from the Department of Breast Surgery in Hospital 1 had positive views of informed consent. He believed, informed consent was used to remind professionals to offer full information to their patients (interview 8).

Although institutional design involved informed consent, some professionals believed that more involvement should be encouraged by specific policies.

'The hospital requires us to tell all options to patients. Everything needs to inform patients and share decision-making, unless emergent conditions happen. But I think policy-makers should encourage patients to be involved in the process, especially as we talk much about personalised health care. Treatment plans should be made on the basis of many factors, including conditions, genetics, physiques, social and economic issues. I think we need

a high level of patient involvement and participation.'

(Interview 3, Surgeon, Department of Urinary Surgery, Case 2)

The evidence from professionals demonstrates the understanding of medical ethics in China. Informed consent works as the limited means to provide information due to the relative lack of communication between professionals and users. As the evidence of agreements, it plays a key role in preventing medical disputes by achieving written documents between providers and users. Before the application of informed consent policies in China, according to the respondents, most agreements were achieved in an oral form and trust was maintained between professionals and patients. However, informed consent does not really value the preferences and views of patients. It provides information of illness to patients and/or key family members but lacks two-way communication. Users are given limited choices through informed consent. They also take all the risks and responsibilities, including the overtreatments, mistreatments and post-treatment risks. Thus, informed consent does not really contribute to the enhancement of trust and service improvement. Participation is not well valued even though informed consent is ensured.

5.3.2.2 Viewpoints of health board managers

I conducted individual interviews with health board managers who were working in local hospitals in three selected cases. These health board managers were key stakeholders who were managing health services and implementing health policies. They provided valuable insights into the issue especially those who were working with service users. I used a snowballing strategy to access potential interviewees in the three field sites. I ask: How do you understand the functions of health facilities and the role of service users? Do you think service users should be involved at the clinical level of service delivery? What about engagement at organisational and system levels?

1. Understandings of health service delivery

Health board managers talked about their understanding of service delivery, when I asked them to whom they believed services were delivered. Most health board managers recognised that health services were not only provided to patients, but the general public. Two managers from Hospital 3 mentioned the importance of illness prevention. One respondent said, there were three levels of health services: the first level was illness prevention and health education for the population; the second level was health intervention with high risk groups; the third level was intervention with patients who had diseases (interview 9). She said health service delivery took on many social responsibilities. The other interviewee from this hospital also emphasised that services were provided to the general public, such as the provision of free medical examinations every year (interview 10).

Two interviewees mentioned that health services were provided to patients. One of them, who was Director of a department in Hospital 3, criticised that many patients became consumers, which was against the principles of health care (interview 14). Another respondent, who was Director of a department in Hospital 2, believed that health services should also be provided to special groups, such as elderly people, people with diabetes, women and children. (interview 11).

I then asked: Do you think patients are passive or active? Responses were various. Three managers thought patients were passive because they knew little about health care.

'The people I meet every day have very poor awareness and knowledge of health. We have free examinations every year, special for patients with diabetes and high blood pressure. We also offer four follow-up visits. But they do not follow our advice... Most people are not aware of keeping healthy.'

(Interview 11, Case 2)

The other manager in the county hospital, said that professionals were more

powerful and took control of resources, compared to patients who had poorer medical knowledge (interview 9).

A manager, who used to be the former associate dean in Hospital 2, argued that patients were both passive and active (interview 12). On the one hand, they were only accepting services provided by professionals and hospitals. On the other hand, they were able to request services they wanted.

The manager, Director of a department in the Hospital 3, believed that patients, despite being powerless, tended to be more active in the marketised health system, as they gained rights for receiving information and making choices.

'Most of them visit hospitals themselves. Informed consent is ensured during the process of treatments. They can make choices, too. In general, I think they are more active.'

(Interview 9, Case 3)

Another manager from Hospital 3 talked about changes in patients' roles, compared to the old days when medical technology and information were poorly developed. He also thought patients had been more active than before.

'I think they used to be very passive. However, patients have better understanding of medicine and health care, with the development of technology, internet and mass media. They are not passive in many ways. They are able to talk with doctors with information they control.'

(Interview 10, Case 3)

I also asked the managers about understanding of service providers. Indeed, a manager in Hospital 3 questioned the term 'service provider'. She gave me an example why hospitals were not typical service providers.

'I think hospitals are not only service providers. It is a place for saving lives. For example, patients complained to us because someone jumped the queue. We made it happen because the patient was in an emergency. But people thought it was our fault to make it happen. We gave explanations to them, but they felt it was not forgiven. They thought our services were terrible.'

(Interview 14, Case 3)

She complained about the failures caused by market mechanisms in the health sector. Hospitals were supposed to be a service provider in the market setting, which went far away from the nature of health care. Others also affirmed that health facilities had a more social function, than economic entities. A manager in the county hospital also asserted that hospitals are more like governments:

'Hospitals are many functions. Service provision is only a part of them. Moreover, hospitals also function like governments. They provide public health services and disease control.'

(Interview 10, Case 3)

2. Involvement at the clinical level

To evaluate attitudes towards patient involvement and participation, I asked health board managers if they thought service users should be involved in health care delivery. Unlike professionals, health board managers seemed to have contrasting viewpoints.

Some managers thought patients should not be involved in the health delivery process due to the lack of health knowledge. These views were based on their personal experiences of engaging with patients.

'I think patients are not so important in this case. Health care is a knowledge-

intensive area. Although most patients have basic common sense, it is very possible that they have other unreliable sources of information, such as Baidu. I think their roles are just 'co-ordinators', as they really have quite poor health literacy.'

(Interview 14, Case 3)

Another manager, who supported exclusion, compared the professional-patient relationship as teachers and students.

'This is the same with teachers and students. Students are accepting knowledge and training. In my opinion, doctors should be more active. Most patients really have poor health literacy with little education. In this case, patients are responsible for providing information of symptoms, and doctors make judgements and decisions.'

(Interview 12, Case 2)

He insisted that many patients had a poor capability to accept their condition. That was why cancer was always told to family members, instead of patients.

'If you tell them their condition directly, there would be a terrible consequence.'

(Interview 12, Case 2)

While some managers objected to involving patients at the clinical level, other respondents claimed that patients' involvement was important in health care delivery. A manager from Hospital 2 said it was possible to involve patients because service users often showed good health knowledge (interview 11). Another respondent from Hospital 1 argued that patients could be involved in health care decisions to some degree, depending on disease-type and seriousness of condition (interview 13).

3. Involvement at organisational and system levels

To probe their attitudes towards involving patients in managing health services, I asked: Do you think service users should be working with you in managing health services?

Four respondents thought patients should not be involved in managing health facilities. A respondent argued that it was not feasible in the current health system.

'This is not suitable in China, because we don't have the system. It won't work.'

(Interview 9, Case 3)

She revealed that it was not popular for hospitals to work with service users. Health board managers only allocated and managed services of health care and implemented health policies.

The other reason for no involvement was the lack of experience or knowledge. A manager from the county hospital thought patients knew nothing about how to run and manage a hospital.

Nevertheless, three managers believed that patients should be involved in managing hospitals. One respondent from the county hospital gave an example that proposals from service users could improve service quality. Another respondent from the city hospital also mentioned that users can supervise services.

I also asked them about their attitudes towards involving patients in policy-making. Surprisingly, most respondents believed it was necessary to involve service users in making health policies. For instance, a manager from Hospital 2 talked about the benefits of involving users in designing services

and policies.

'I think people should have a say, as health services are provided to them. They know exactly what they need and what they want. I think the most effective way is asking service users. But you know, it is rare practice to involve them.'

(Interview 11, Case 2)

However, many respondents mentioned difficulties when engaging with service users in the policy-making process. For example, a manager from the county hospital talked about shortcomings of user involvement in the process.

'I think users should have a say. But I doubt how much they can influence policy-making. This should be quite different from what policies are made now. Service users might only consider their own things; they seldom consider problems as a bigger picture. This is different from policy-makers. So yes, but it remains uncertain whether it can work or not.'

(Interview 10, Case 3)

Another manager in the city hospital pointed out that it depended on what policies patients might be involved in.

'For some policies, it is necessary to involve people in making policies and designing services. For example, they can be invited in designing a health insurance scheme, payments and design of basic medicine category. But they have no say in some policies, such as the regulations of health facilities.'

(Interview 13, Case 1)

Another manager from Hospital 1 told me she was hesitant about it, as policies made changes slowly and it might be impractical to involve users in

many cases.

'Yes, they should have a voice. However, it is not easy for policy-makers to invite everyone, I suppose. And policies are making changes slowly. For example, the referral system of health insurance users has been a problem for years. Relevant authorities are aware of it, but they make slow changes, because it is a problem with lots of conflicts. I think involving patients in policy-making is really difficult. The process of policy change and improvement is a long journey.'

(Interview 15, Case 1)

Only a manager from the city hospital was opposed to involving service users in policy-making.

'I think patients should have no say in policy-making. This is not buying a property. Health care is a very professional area.'

(Interview 12, Case 2)

5.3.3 Institutional comparisons across cases

I found there were significant differences in desire for involvement across the three cases. Based on the responses of the interviewees, I distinguished three levels of involvement: exclusion; information receiving; shared decision-making. I calculated frequencies of responses for each level of involvement (see Table 16). In Case 1 and Case 2, desire for exclusion only accounted for 29% and 13% of responses. In contrast, the proportion of responses for exclusion was 50% in Case 3, respectively. Meanwhile, there were 50% and 58% responses of SDM in Case 1 and Case 2, respectively, while only 17% of SDM in Case 3.

Table 16 Comparison of desire for involvement across cases

Frequency of responses	Exclusion	Information receiving	Shared decision-making	In total
Case 1 (City hospital)	7	5	12	24
Case 2 (City hospital)	3	7	14	24
Case 3 (County hospital)	6	4	2	12
In total	16	16	28	60

Source: author's own data

Missing value: 0

Overall, differences of desire for involvement between city hospitals and the county hospital are noteworthy. I find institutional factors accounting for existing differences. In the following sections, I compare these institutional factors across health facilities and service users.

5.3.2.1 Comparisons of health facilities

1. Institutional design

In my temporary role as an intern working in each selected hospital, I have the opportunity to learn about their institutions. Hospital 1 and Hospital 2 are two tertiary hospitals, which are at the top level in China. They provide health services to the population of the city, including all districts and counties. They are also open to service users from other areas, as some clinical departments enjoy good reputations. Under the supervision of the same health administration bodies in the city, they have similar institutional designs. They all have quality improvement strategies like conducting patient satisfaction evaluation every two weeks (interview 15). They also monitor medical accidents and seek to reduce the rates of malpractices (interview 13). By contrast, Hospital 3 is a secondary hospital located at the county level. It mainly provides services to local residents, mostly rural dwellers. Few service users beyond the area visit the hospital, as it is unable to provide advanced medical services.

Health facilities at the top level in China are given much autonomy in making

and implementing new initiatives, such as quality improvement measures. For example, user involvement in patient safety has been widely promoted in clinical departments at state level since 2015. In Hospital 1 and Hospital 2, specific regulations regarding patient rights and responsibilities were carried out and demonstrated to service users on the wall of clinical departments before the year of 2015. Hospital 3 has not initiated user involvement in patient safety (interview 14). Much more emphases are given to the evaluation of patient satisfaction in Hospital 1 and Hospital 2 (interview 15 & interview 11). In terms of patient involvement and participation, there are no extra efforts except for informed consent and information transparency in Hospital 3 (interview 14).

2. Human resources and knowledge exchange

Tertiary hospitals in China carry out research in all aspects of clinical practice. This is reflected in the two city hospitals. Hospital 1 is a teaching hospital and affiliated to a local medical college. Hospital 2 is a research-based health facility, although it is a non-teaching hospital. These research-based facilities employ a large number of highly specialised staff members with various educational backgrounds, qualifications and training. For example, licensed physicians should at least obtain a Master's degree in medical sciences, with many having doctor's degrees (interview 12 & interview 15). However, secondary hospitals have limited teaching and research capacities. As a non-teaching hospital with little research, the standards for recruiting health professionals in Hospital 3 are lower than tertiary hospitals. Licenced physicians only require a Master's degree with a small proportion having a doctor's degree (interview 14). Those gaps in available human resources translate into different understanding of professional-patient communication in practice. Professionals in city hospitals are more likely to embrace patient involvement (interview 11 & interview 15), while professionals in county hospital are less likely to give patients more power in decision-making (interview 14).

In terms of knowledge exchange, opportunities are significantly different between tertiary hospitals and secondary hospitals. Health professionals in Hospital 1 and Hospital 2 receive more funding from governments for training,

conferences and academic exchanges. In Hospital 3, professionals mainly focus on daily medical practice, and fewer opportunities exist for personal development. Besides funding sources, the gap is due to existing differences between professionals' capacities in tertiary and secondary hospitals (interview 12 & interview 14). Without opportunities of knowledge exchange, professionals and managers are unfamiliar with patient involvement and participation, and less likely to understand the value of user contributions in health service delivery.

5.3.2.2 Comparisons of service users

In some interviews, professionals and managers talked about differentiation of service users. 'Urban users' and 'rural users' were frequently mentioned by respondents. Professionals discussed the urban and rural users' different capacities to understand health care and their willingness to engage with professionals. For example, a professional from Department of Breast and Thyroid Surgery in the county hospital argued that it was normal to give recommendations for treatment plans, after informing patients and/or family members details of conditions, pros and cons, and recurrence rate.

'Most of patients and their families are rural residents. They know nothing and they have no other information sources. We often recommend treatments to them and they normally trust us.'

(Interview 7, Department of Breast and Thyroid Surgery, Case 3)

In contrast, a professional in one of the city hospitals said he mostly asked service users to choose treatment options, as many patients were active in making choices and had various information sources.

'Patients have their own strategies. They are able to seek various opinions from many professionals. They make their own judgements. They also search the internet. Patients in the city are very different from rural people.'

(Interview 8, Department of Breast and Thyroid Surgery, Case 1)

Health board managers also mentioned differences between service users, when asked about user involvement at clinical, organisational and system levels. For example, managers in the county hospital thought that their patients had no capacity to engage with professionals (interview 14 & interview 9).

Managers in the city hospitals supported this view. The manager in Hospital 2 talked about difficulties of engaging with rural residents.

'For residents who live in cities and districts, they have better understanding of health care. But people who live in rural areas have poor awareness of health. Many are not able to understand what you mean. I ask them if they really understand what I mean, they say yes. But if I ask them to explain to me, they don't really know the meanings.'

(Interview 12, Case 2)

The other manager in Hospital 1 believed that patients in bigger cities were more active than those in small towns and counties.

'Patients in bigger cities have capacities to engage with health facilities. They also have high requirements of health services. But people in rural areas are still passive and reliant on professionals.'

(Interview 15, Case 1)

5.4 Summary of findings

In this chapter I explored wider the policy and institutional contexts of patient involvement and participation. The first policy context looks at the key aspects of the Chinese health system reforms since 2009, which explains why patient rights and involvement are not given enough attention by policy-makers. The second policy context includes the policy institutions' roles in

policy-making and implementation in China. Policy-making is largely dominated by the central government, although interactions among bureaucracies are complex and difficult. Local authorities have limited influence over policy-making, but they have flexible autonomy in policy implementation. Current policies and legislation seem to reinforce rights to information, with little emphasis on treatment decision-making. In addition, policies also protect rights of family members for information. Local policy administrators supported the view that policy-makers did not value user involvement and participation. This was mainly due to the belief in market mechanisms and resource scarcity.

Due to little policy support, the practice of patient involvement and participation is promoted at the organisational level, such as informed consent, 'patient-centred care', and user involvement in patient safety. Health professionals and health board managers from three hospitals provide insights into understanding and values regarding this issue. Although most health professionals highly value user involvement in the process of health care delivery, it may not be applicable in emergency conditions. Professionals understand 'involvement' differently: some think it is information-giving, some limit SDM to discussing treatment options, and some believe it is crucial at all stages of health care. Compared to interviewed surgeons who prefer to implement SDM, physicians like to recommend treatment options. Most professionals are in favour of involving family members in health care decisions, as they regard them equally important in coproducing health care. A range of factors, identified by professionals, is likely to affect people's desire for involvement and participation, such as educational background, costs and side effects. Professionals also hold contrasting views of informed consent: some think it implies a distrustful relationship, while others believe it helps ensure full information. Nevertheless, some professionals think more involvement should be encouraged by policies.

Most health board managers believe that services are provided to the general public, although some confine it to patients or special groups. Some think patients are passive, while others believe they are not in the market

system. Managers are doubtful of the definition of 'service providers', as this leads to hospitals being seen as economic entities. Some managers value user involvement at the clinical level to a certain extent, even though others object to it. They also have mixed opinions of involvement at organisational and system levels. Some managers approve of the values of user contributions to quality improvement and policy-making, but the main barriers at higher levels include infeasibility in the existing system and lack of experience or knowledge of management or policy-making.

Promotion of user involvement seems to be heterogeneous, varying from organisation to organisation. In the cross-case comparison of people's desire for involvement, I find that users in city hospitals embrace shared decision-making, compared with those in the county hospital. Institutional factors can explain existing differences. In terms of institutional design, city hospitals are more inclined to improve service quality with the design of user involvement in their institutions. They also have better human resources and more opportunities for knowledge exchange, which explains why user involvement is better in tertiary hospitals. Differences between service users are another important factor. Users who live in the city are more active in seeking information and engaging with professionals, while users who are rural residents are more passive and dependent.

Although Hospital 1 is a teaching hospital and Hospital 2 is a non-teaching hospital, the analysis does not show any significant differences in promoting patient involvement and participation. Firstly, the institutional design does not demonstrate any differences. They are both tertiary hospitals. They both have the institutional design of quality improvement, making efforts in evaluating user satisfaction and taking the measures of improving care quality, i.e. the introduction of some involvement in patient safety. Meanwhile, the staff in both hospitals are relatively well qualified and trained. They all seem to have academic input and they claim that they are teaching/research-based hospitals. Both hospitals encourage staff to be involved in international networks and conferences, where patient involvement would be relatively high on the agenda. However, there is little difference to be observed. In addition, the service users of Hospital 1 and Hospital 2 are from both urban

and rural areas, although they are city-based hospitals. Overall, the analysis shows that the differences between Hospital 1 and Hospital 2 are not significant.

5.5 Concluding remarks

While Chapter 4 explores the political context of patient involvement and participation at the macro-level, Chapter 5 attempts to concentrate on macro- and meso- levels of context, from the perspectives of local administrators, academics, health professionals and health board managers. Specific policy contexts are given to explain why patient involvement and participation is not promoted as a system-wide practice. The institutional context is identified as to what practitioners think of patient involvement and other related issues. Based on the cross-case comparison, other institutional factors are found to explain the variety of promotional practices. In the next chapter, I am going to analyse the individual context of patient involvement and participation at the micro-level in China.

Chapter 6 Taxonomy and Contexts of Involvement and Participation

6.1 Introduction

The chapter mainly focuses on patient involvement and participation at the clinical level of health care. While a range of models of patient involvement are illustrated in the literature, a taxonomy of involvement and participation has never been developed in the Chinese context. In this chapter I provide intensive analysis of patterns and contexts of behaviours and willingness for user involvement in health care delivery. I will argue that the individual, cultural and social contexts significantly affect how users wish to be involved in their health care. Age, disease-type, health insurance type, seriousness of condition, doctor-patient relationships are all determining factors. Cultural capital and the family context are also associated with the willingness for involvement in health care.

In Section 6.2, I describe five types of actual involvement and three types of desired involvement, drawing from the responses in the first stage of interviews. Thus, I attempt to answer the questions: To what extent are service users involved? To what extent do they wish to be involved? In Section 6.3, I explore 'contexts' to understand the situations or positions that give meaning to involvement and participation. Based on the literature and empirical data from 95 interviews at the first stage, I identify various contexts of involvement, including individual, cultural and social contexts. I first examine how individual attributes affect patients' attitudes and desire for involvement and participation, such as disease-type, stages of cancer, seriousness of condition, age, health insurance type and doctor-patient relationship. Then I compare how people with different levels of cultural capital show differences in their willingness for involvement in health care delivery. Subsequently, I explore how the social context, namely the family context and social capital, affect their attitudes towards involvement in the decision-making process.

Based on this analysis, I develop tentative hypotheses on which factors are likely to affect people's attitudes and desire for involvement and participation in Section 6.4. In Section 6.5, I deductively test the hypotheses, using data

collected in the second fieldwork. In Section 6.6, I discuss the results of qualitative analysis and summarise the determining factors associated with desire for involvement and participation. Section 6.7 is a conclusion of the chapter.

6.2 Taxonomy of involvement and participation

6.2.1 Who are involved in health care decisions?

Conducting semi-structured interviews with inpatients in four clinical departments in each of three hospitals, I focus on the extent to which patients are involved in health service delivery. The question attempts to examine who makes decisions and how decisions are made in the process of health care delivery. A few questions are asked to explore the interactions: Can you share the experience of engaging with health professionals in the treatment process? Who makes the decisions for your treatment? Do you need to ask your spouse or siblings to make decisions? If so, why do you think you should ask them?

While telling the stories of how they are treated, a range of descriptions of involvement are given by respondents. In practice, involvement is seen to be much more complex, as several parties are involved in the process. On one side, health professionals, referring to doctors by respondents in the dialogue, are the main participants in health care decisions. On the other side, patients, along with their key family members, who are regarded as lay carers, are the other important participants. Similar to many western contexts, as mentioned by Thompson (2007, p. 1302), lay carers are playing supplementary or alternative roles in involvement under some circumstances; e.g. when patients are physically disabled from making decisions or when they are psychologically unable to know their condition.

However, a special context, identified in the fieldwork, is the priority of involving family members. In practice, key family members in China are prioritised to give information or make decisions with professionals, especially when patients' conditions are not good; e.g. cancer. Patients are

not regarded as the first person to talk to, unless the illness needs their cooperation. Furthermore, professionals and family members may exclude elderly patients from decision-making due to psychological stress. As required by regulations, patients should not be given any information when their family members do not approve.¹⁹ Therefore, I could only access patients whose families give information about their condition or illness. A few cases like this are identified in the fieldwork, where family members are involved in health care decisions without the patient being involved. More specific questions in regard to their attitudes towards family involvement will follow in the latter sections.

6.2.2 To what extent are you involved?

Five levels of taxonomy are identified and abstracted from data. This is drawing upon the taxonomy of patient involvement by Thompson (2007, pp. 1302-1307), especially in terms of information and decision-making. I choose to use a taxonomy developed by others, rather than my own taxonomy. This is mainly because many concepts are new to Chinese service users, such as 'patient involvement', 'information seeking', 'treatment decision-making'. When I mention 'patient involvement' in the pilot study, most respondents ask me what it means. With the existing taxonomy, I am able to give the concepts more precise descriptions and specific examples.

6.2.2.1 Paternalism

Paternalism, drawn from the taxonomy of patient involvement from previous studies, is used here to denote the pattern in which decisions are solely made by health professionals. Respondents give the description of paternalism, if they rely on their professionals (mainly referring to their doctors) all the way and exclude themselves from obtaining information and the decision-making process. Regardless of their condition, patients leave decision-making to health professionals, although lay carers may be given information in some

¹⁹ For example, the Law of Practising Physicians specifies that professionals should avoid making negative impacts on patients; informed consent can be obtained from their family members (National People's Congress of China, 1999).

cases.

“The doctor makes the decision, for example, whether I need an operation or not. Key family member should sign the form, but we let the doctor make all the decisions.”

(Interview 0904, female, 64, rural resident, Gastric and Intestine Department, acute condition, little education)

Some believe that their roles in the service delivery process are passive. A respondent describes it as ‘being treated’.

“The doctor makes decisions, for example, giving me pills and injections. They are in charge of that. I think it not necessary to discuss with the families and myself, as we are here to be treated.”

(Interview 1203, female, 62, rural resident, Cardiology Department, chronic condition, no education)

6.2.2.2 Professional-determined

‘Professional-determined’ refers to the situation when decisions are largely dominated by health professionals, with information being given to patients (and lay carers). It is the most common situation, with over half of the responses claiming they are involved in such a process. Many respondents said it occurred naturally, when professionals needed to tell them everything (or mostly) and seek their consent for treatment. A recurring situation is that patients (and lay carers) are faced with some options when they are given information, and they ask health professionals to recommend a treatment. Many respondents think that information is highly important, but they would leave decision-making to their doctors.

A woman, who had broken bones in her foot, told me that her condition was complex and difficult to recover from soon. She found it difficult to have any

ideas when the doctor came up and asked her preferences of treatments. She just told the doctor to make decisions, but she wanted to know what happened in every stage.

‘The doctor made the decision, of course, as we didn’t understand it at all. But the doctor also knew my attitudes and he wanted to achieve agreements with me, although he made most of the decisions.’

(Interview 0802, female, 66, Emergency Department, acute condition, no education)

Another woman who has had coronary heart disease for five years mentioned that she faced the option of accepting an angiography or not. She told the doctor to make the decision, but she told me she knew there were options.

‘The doctor made the key decision, but he let me know that there were two options: one was having the angiography and vascular stent, which seemed to be more positive; the other was a conservative treatment—having pills.’

(Interview 0304, female, 67, urban employee, Cardiology Department, chronic condition, well-educated)

6.2.2.3 Shared decision-making

The pattern of SDM was understood as the full exchange of information and sharing of decision-making power. According to interviews, many respondents saw the process positively and stressed the importance of an ‘equal position with professionals’. Some revealed that discussions were necessary, as they might have a trade-off, express their wants or worries, or consider the issue of costs.

Patients with breast cancer talked repeatedly about preferences. A woman, who had been newly diagnosed with breast cancer, told me that she wanted

to tell the doctor she felt safer with a mastectomy, although the cancer was in the early stage. She was afraid of recurrence if she chose a breast-conserving treatment.

'The doctor asked about my opinions, whether to excise or maintain the breast. I would like the excision and I needed to make sure it did not happen again. So we discussed together, along with my family.'

(Interview 0608, female, 61, rural resident, breast cancer, no education)

A man who had a heart attack a week before the interview told me that this family told him about the condition. He felt stressed about health care costs if he had to place vascular stents. He involved professionals and his family in the discussion, as he wanted to ask his professional if it was all right to use cheaper stents.

'We discussed together. They asked me whether I wanted vascular stents or not. I think I had to do it, otherwise it would be dangerous any time. But I needed to consider the costs, as there were two different kinds of stents with two prices. I told the doctor that I wanted to use the cheaper one, and I hoped he could give me cheaper medication.'

(Interview 0301, male, 63, rural resident, Emergency Department, acute condition, little education)

Some respondents claimed that they had a sense of responsibility for health and they felt obliged to fully participate in the process. Many respondents mentioned their family members and used the word 'we' when they described shared decision-making.

'I think I should be involved all the way, as it is important for me. The doctor informs us of everything. We should all participate in the decision-making process.'

(Interview 0803, female, 37, urban employee, Emergency Department, acute

condition, well-educated)

6.2.2.4 Patient-lay carer determined

Only a very small number of respondents mentioned the 'patient-lay carer determined' pattern, that information was sought actively by patients and their families, and decisions were made mainly by them. Under the circumstances, patients were confident with their competence in illness management. They also had ideas and preferences about how to treat themselves.

A woman who had an accident said she made the decision with her family, after receiving information from her professional.

'I made the decision, along with my family. We sought advice from the doctor. The doctor couldn't force us to accept some treatment, if we were not willing.'

(Interview 0805, female, 57, rural resident, Emergency Department, acute condition, little education)

6.2.2.5 Autonomous decision-making

This was a less common but additional possible response. 'Autonomous decision-making' occurred when patients highly valued their own knowledge of health care and felt a strong responsibility for their own health. In such a case, patients did not necessarily need any information from health professionals and they did not give the power of decision-making to anyone else.

'I made my own decision, as the professionals had no better treatment scheme.'

(Interview 0102, male, 52, urban employee, Cardiology Department, chronic condition, high school education)

6.2.3 To what extent do you wish to be involved?

While I explored the experience of involvement and participation, I also asked whether or not they were happy with it. Some people felt that they would stick to the way they currently engaged with professionals, but others claimed that they would prefer an alternative pattern. To explore their desires, I asked the patients 'to what extent do you wish to be involved in the process of health service delivery?' I prioritised the patients, rather than lay carers, as their wishes were my main interest. Even when lay carers responded to the questions, I also asked patients for confirmation. In the following section, I discussed with respondents their desire for getting involved and reasons behind it.

6.2.3.1 Desire for exclusion

Many respondents said they would rather have no involvement in the process. Reasons for the lack of motivation included having trust in professionals, little confidence with their own health literacy, little experience of health care, and the psychological burden.

An old man who has had coronary heart disease for over ten years noted his reason for being passive, believing that professionals were superior to his family and himself.

'I would rather the doctor makes all decisions, as they are more professional and careful than we are.'

(Interview 0501, male, 88, urban employee, Cardiology Department, chronic condition, little education)

A middle-aged woman, who received little education, revealed that she had no concept over how to be treated, nor willingness to considered it. She expressed her unwillingness to engage with professionals.

'I preferred that the doctor made the scheme for me, as I really could not understand it, nor did I like to think about it. It was better for the doctor to make all decisions.'

(Interview 1004, female, 47, rural resident, breast cancer, little education)

Another lack of motivation derived from the unfamiliarity with health systems, as respondents had little experience of health care.

'I think we should let the doctor make key decisions, as we don't understand many procedures and process of treatment. We have to rely on doctors.'

(Interview 0809, male, 64, rural resident, Emergency Department, acute condition, little education)

Respondents also mentioned their perceptions of the professionals' role. Some believed that health professionals took the role of healing patients, which was more important than the patient's role. One respondent stressed that he would feel upset if his doctor did not make decisions for him.

'If they insisted patients to make decisions, I felt the doctor was not responsible. We came to the hospital for treatments and we trusted the doctors.'

(Interview 0901, female, 27, urban employee, Gastric and Intestine Department, acute disease, well-educated)

Similarly, another respondent demonstrated his understanding that patients should support professionals during the treatment process.

6.2.3.2 Desire for receiving information

Many respondents expressed their desire for more information, although they disliked decision-making. Many said they would ask for more when

professionals were giving information about their condition. The motivations for more information included the need for self-management, knowing the effects of treatments on life, and the right to know what happened.

Some patients with chronic conditions preferred to have more information, as they needed to manage illness in the long run. An older man, who had been newly diagnosed with coronary heart disease, wanted to know more about the illness, as he was a new patient. He also realised that it was a long-term condition, which he had to manage on his own.

'I wish to know more, as I want to know what treatment I have to do in the long term. Heart disease is a chronic illness. It is very uncomfortable sometimes. I think I should know more from the doctor, as I feel I am responsible for myself.'

(Interview 1105, male, 66 and above, urban employee, Cardiology Department, chronic condition, well-educated)

Some patients with breast cancer had a desire for information, including the effects of treatments (e.g. operation, radiotherapy, or chemotherapy) on their quality of life. A woman who just had a mastectomy knew from her family that she had breast cancer. She told me that she wished to know more, as she was worried that the operation affected her arm, with her lymph gland removed. She was also worried about the upcoming chemotherapy.

'I preferred to know the adverse effects on me, about the operation and chemotherapy. I also needed to know how I could maintain health afterwards.'

(Interview 0608, female, between 51 and 65, rural resident, Breast and Thyroid Department, breast cancer, no education)

Some patients had no experience of illness and needed more information to decide what to do next. A woman and a man were both recently diagnosed with coronary heart disease. They were anxious about their illness.

'I needed more information, so I consulted with my doctor in his office. I needed to know what to do at the next stage.'

(Interview 0101, female, between 51 and 65, rural resident, Cardiology Department, chronic condition, no education)

'I was just sent to hospital. I really needed to know what happened.'

(Interview 1206, male, between 51 and 65, rural resident, Cardiology Department, chronic condition, little education)

When they talked about why they preferred to leave decision-making to others, reasons given by respondents were the same as exclusion from decision-making, such as a belief in 'professionalism' and 'little confidence in their own health literacy'.

6.2.3.3 Desire for sharing decision-making

Some respondents were keen on shared decision-making. Their motivations included the consideration of costs and preferences over treatment.

A man, whose condition was severe, mentioned that he had spent a lot of money on health care, as he wanted to live longer. However, he was very anxious to learn about cheaper treatments from professionals.

'I preferred that treatment decisions were made on the basis of sharing information and opinions. It was mainly because I needed to consider costs, as I really had to think over whether my family could support the burden of it or not.'

(Interview 0102, male, 52, urban employee, Cardiology Department, chronic condition, high school education)

Another patient with a chronic condition mentioned a similar situation. He explained why he rejected an operation due to it being too costly.

'I preferred to share decisions, as I did not want to have an operation – I wanted to just have pills. Having an operation was very expensive for me.'

(Interview 0402, male, 60, rural resident, Cardiology Department, chronic condition, little education)

Some other respondents, who have been ill for a long time, demonstrated a high confidence in their health knowledge and a good control of their illness. An old man who has had coronary heart disease for more than 10 years, told me that he knew a lot about his disease, as he read materials and tried many kinds of medication. He was also aware of the responsibility of controlling his condition.

'I like to share decision-making, as I am doing research on my own disease every day. I feel that I have a say in the treatment scheme.'

(Interview 1204, male, 73, urban employee, Cardiology Department, chronic condition)

6.2.3.4 Desire for patient-lay carer determined and autonomous decision-making

No respondents in the interviews revealed their willingness to make decisions mostly or all by themselves. When asked why they could not make decisions without professionals, most respondents said they believed health care was a very professional area. They felt they lacked the confidence to rely on themselves.

6.3 Contexts for desiring involvement

The taxonomy of desired levels of involvement in Section 6.2.3 provides

explanations for why some patients like to get involved and others do not. While respondents seem to be clear about their desired levels of involvement, contextual factors that determine people's willingness for involvement are worth exploring. Previous studies examine factors associated with people's desire for involvement, such as sociodemographic conditions, type of disease, seriousness of condition, experience or knowledge of health care, professional-patient relationship (Benbassat et al., 1998; Blanchard et al., 1988; Coulter and Ellins, 2007; Rosén et al., 2001; Strull et al., 1984; Sutherland et al., 1989; Thompson, 2007). However, little research contextualises these factors within the Chinese health system. In this section, I carefully examine the associations between contexts and people's willingness for involvement and participation in China. A couple of factors are identified in the first stage of fieldwork, including individual, cultural and social contexts. The contextualised factors will enrich our understanding of the meaning of patient involvement and participation in Chinese hospitals. In the following sections, I will demonstrate the evidence I gather in the first stage of fieldwork.

6.3.1 The individual context

First, I attribute some contexts to individual situations. In the fieldwork, I attempt to explore which individual factors affect people's attitudes or willingness to be involved in health care delivery, particularly health care decision-making. Incorporated with ideas from the published literature, I discuss aspects with service users, including the type of disease, stages of cancer, perceived seriousness of condition, sociodemographic characteristics, socioeconomic status and patient-professional relationship.

6.3.1.1 Type of disease

Some studies demonstrate that patients with chronic conditions are more willing to be involved in health care decisions, based on their extensive experience of illness management (Entwistle et al., 2008; Greenhalgh, 2009). The accounts given by respondents with chronic conditions also confirm that they feel very confident in managing their conditions and in controlling of the

treatment process. This is mainly due to their everyday experience of coping with long-term illness.

'I go to the hospital many times. I know staff very well. I will tell them if I have problems. They know my conditions and clearly know what tests and medications I should have. The doctor won't change my prescriptions if I don't agree. They always ask my opinion if they want to make some changes of treatments. I also ask them why they change it...I feel I am an 80% doctor now.'

(Interview 0506, male, 75, urban employee, Cardiology Department, chronic disease, well-educated)

On the contrary, patients who have acute conditions reveal their unwillingness to be involved in the process. This is mainly because the conditions occur suddenly, and they have no experience or knowledge of how to control it.

'It is crush injury... I feel so sudden... I need to ask my doctor to make decisions. This is because he is very familiar with the illness while I only came across it for the very first time.'

(Interview 0804, female, 33, urban employee, Emergency Department, acute disease, well-educated)

Overall, I make the following tentative hypothesis: patients with chronic conditions are more likely to want to be involved than patients with acute conditions.

6.3.1.2 Cancer

Patients with cancer are categorised as a separate group because the conditions are perceived as acute in primary stages and chronic afterwards. Scholars recognise that involving cancer patients is crucial for improving

health outcomes (Coulter, 2003). However, the stages of cancer may affect how much patients want to get involved. Some patients with stage I and II come across choices of breast-conserving treatment (BCT) and mastectomy. Other patients meet the situation when professionals want to discuss chemotherapy or radiotherapy. Some who have completed treatment also have to talk with professionals about hormone therapy.

It seems that patients in preliminary stages (e.g. diagnosis of cancer; BCT or mastectomy; chemotherapy or radiotherapy) are more reluctant to be involved in the decision-making process due to the stress or lack of confidence. However, patients who have no recurrence in later stages of treatment (e.g. hormone therapy or medication) tend to be more active, if previous treatments are successful. Some women who have completed their chemotherapy claim that they are very eager to know more about the hormone therapy when they know the outcomes of chemotherapy are good. They would ask for more details about medications and other suggestions from professionals. Some seek information from other sources before they talk to professionals. They feel prepared to engage with professionals.

For cancer patients, sharing decision-making never seems to be easy. Many respondents choose to leave decision-making to others (e.g. professionals and family members), although they want to know what is happening. This is particularly the case when they mention BCT. They said they felt unsafe to keep the breast although they wanted BCT. In the end, many cancer patients left the decision to their doctors or asked their family members to talk with professionals. For those patients who had almost completed therapy, they also said they regretted their decisions when 'everything turned out better now'.

Therefore, I make the following tentative hypothesis: the later the stage of cancer, the more likely that patients are willing to be involved in their health care.

6.3.1.3 Seriousness of condition

Previous research demonstrate the association between seriousness of condition and desire for getting involved in health care (Thompson, 2007, p. 1308). This is also reflected in the interviews. Some respondents reveal that their motivation to engage largely depend on how serious they perceive their condition to be. For example, some patients, who perceived their conditions as not serious, claimed that they wanted greater involvement, as they felt confident to understand the situation and talk with professionals. A young woman, with a diagnosis of acute appendicitis told me she was very involved in the treatment and sought advice from a second opinion online.

'It is not life-threatening, but very annoying. I feel I want to know more. I search the internet as I have a doctor online. I also consult with him when I get all results of tests and examinations. He gives me a reply and I compare with what the doctor tells me here.'

(Interview 0901, female, 27, urban employee, Gastric and Intestine Department, acute condition, well-educated)

In contrast, other respondents, who perceived the conditions as not serious and controlled, told me that they did not want any involvement. The patient, who was also diagnosed with acute appendicitis, chose to be excluded from seeking information and decision-making.

'I felt I have known enough. It was not necessary to know more—acute appendicitis was just like this.'

(Interview 0907, male, 28, rural resident, Gastric and Intestine Department, acute condition, well-educated)

Those who perceived the condition as being serious expressed the wish to be more active in the process, as they were aware of the responsibilities for health care. The man, who recovered from Myocardial Infarction (MI), said he was eager to engage with professionals when he realised it can be very

serious.

'I would like to know every detail of the conditions and my treatments. I often talk with my doctor and discuss the treatments with others who also have the same problem.'

(Interview 0104, male, 65, urban employee, Emergency Department, acute condition, well-educated)

Nevertheless, some patients, although their conditions were serious, expressed their unwillingness to get involved due to the complexity of treatment or psychological stress. This was common among older patients who were less educated and worse-off. Some rejected knowing anything about their illness, as they did not want to know how much they should pay for the costs themselves. Others felt unconfident to engage with professionals.

Overall, for patients who perceive that their condition is not serious, there are two tentative hypotheses: (i) Patients who are confident to talk with professionals, or perceived themselves as educational are more likely to want involvement; (ii) Patients who trust professionals to act appropriately for their benefit are less likely to want involvement.

For patients who perceive that their condition is serious, there are two tentative hypotheses: (i) Patients who believe that they have a personal responsibility (to get better) are more likely to want involvement; (ii) Patients who perceive their condition as complex leading to stress and incomprehension are less likely to want involvement.

6.3.1.4 Sociodemographic characteristics

Some literature outlines how sociodemographic characteristics affect people's behaviours of involvement and participation, such as age and

gender. For example, Blanchard et al. (1988, p.1142) demonstrate that younger patients with breast cancer are more active, while older patients are passive in treatment decision-making. Another study illustrates that men are more passive than women in the doctor-patient relationship (Benbassat et al., 1998, p.84).

It seems that age affects people's willingness for involvement. Many older interviewees told me they did not want greater involvement and would rather leave decision-making to professionals and family members. Some respondents who were lay carers confirmed this. A daughter of a patient with coronary heart disease told me that her mother rarely engaged with professionals. When given two options of treatments, she talked with the doctor on behalf of her mother. Her mother did not want to be in the decision-making process.

'The doctor made decisions and gave some advice. When the treatment options emerged, the doctor came and talked to us, suggesting not to do the vascular stent operation. This was because she was quite old to have it. He discussed with me and I agreed.'

(Patient's daughter, interview 0203, female, Cardiology Department, chronic condition)

Other lay carers stressed that older patients had little health literacy to understand the illness and treatments.

'We discussed with the doctor. But he was too old to understand his conditions, not to mention the treatment.'

(Patient's son, interview 0504, male, Cardiology Department, chronic condition)

In contrast to older patients, younger patients seemed to be more active. Many respondents said they would make complaints or change hospitals

when they were unhappy with services.

'I will talk to the hospital if I am not happy with services. For example, I talked to the staff that the beds were too old and should be changed, and the space was too narrow. Usually I talk to them first and if it does not work, I will consider changing hospital.'

(Interview 0803, female, 37, urban employee, Emergency Department, acute condition, well-educated)

Almost all young patients mentioned the use of the internet, which helped them understand their condition or illness.

'I often use the internet to understand when I am confused; e.g. some indicators of test results and prescriptions the doctor makes.'

(Interview 1009, female, 46, urban employee, Department of Thyroid and Breast, breast cancer, well-educated)

Overall, I make the following tentative hypothesis: the younger patients are, the more likely they want to be involved in their health care.

6.3.1.5 Socioeconomic status

In the interviews, respondents frequently mentioned their health insurance. The coverage of health insurance is related to the socioeconomic status of service users. A UEBMI user, who normally works/worked for the public or private sectors, can get over 70% coverage of their health care costs. However, a RBMI user, who is usually a rural dweller or an unemployed urban resident, is only covered for around 40% and 50%. A study of the experience of Asian American patients with breast cancer also finds that Chinese women choose types of treatment and medication based on their insurance coverage (Tam Ashing et al., 2003, pp. 42-43). Therefore, I asked respondents what health insurance they had and if it affected their attitudes

towards involvement.

In general, it seemed that not many UEBMI users were interested in being involved in health care decisions. Only a small number of respondents who were urban employees, mostly with chronic conditions, demonstrated interest in greater involvement, such as knowing details of their illness and treatment options, as well as the risks of treatment. For example, a man with the diagnosis of coronary heart disease for four years told me that he liked talking with doctors and knew what and why it happened. He talked with professionals about treatment plans and adverse effects of surgery. He also wanted to talk with them about medications. Yet, he said he never wanted to talk about costs, as most of it was covered by his insurance. Patients with UEBMI, regardless of disease-type, often said they trusted their professionals and liked to follow their recommendations in the end.

In contrast, many RBMI users showed motivations for greater involvement in seeking information and making decisions. RBMI users frequently mentioned costs. Even when professionals gave a recommendation of treatment, many said they wanted to discuss alternative treatments due to the lack of insurance coverage. Many RBMI users said they wanted to learn what the cheaper option was and whether it was effective or not. They also felt the need to tell their professionals that some medications were unaffordable. Compared to RBMI users who cared about costs, UEBMI users who liked shared decision-making were more concerned about adverse effects and treatment preferences.

The preceding analysis indicates the following tentative hypothesis: patients with RBMI are more likely to want to be involved than patients with UEBMI.

6.3.1.6 Doctor-patient relationship

Thompson (2007, p. 1308) describes the professional-patient relationship as a determining factor of people's desire for getting involved in health care decisions. Patients might reduce their demand when the trust in

professionals is high. In my research, I start with the exploration of people's opinions of the doctor-patient relationship: Do you think you have an equal relationship with your professionals? Interviewees gave a range of responses. Some felt they did not trust professionals, as there was not much communication between the two sides. Many respondents called themselves 'grassroots', compared to professionals. 'Grassroots' meant ordinary people with little power over decision-making, according to the interviewees. An old man, who has been dealing with his coronary heart disease for 25 years, told me that he felt the relationship was unequal. He stressed that patients were a vulnerable group because of their poor health knowledge.

'I think the doctor-patient relationship should be equal, but it is not. As grassroots, we have to flatter their doctors, as we do not understand anything. If there is any problem with services, many patients dare not complain... They don't understand medicine and they are afraid that they might say something wrong.'

(Interview 0506, male, 75, urban employee, Cardiology Department, chronic condition, well-educated)

Other respondents who distrusted professionals said the relationship was more like a provider-consumer relationship. A man said he just wanted to get well when he paid for his health care.

'I have no concept of trust, as I think I spend money for treatments. I should be healed.'

(Interview 0201, male, 49, rural resident, Cardiology Department, chronic condition, little education)

Most respondents held a positive view of the relationship and felt they trusted their professionals. Reasons for trust included the value of authority and reputation, a good treatment outcome, personal connections with doctors (i.e. doctors are their friends or relatives). Nevertheless, some people mentioned that they 'chose to trust', as they were aware of the gap in health literacy. A

woman, undergoing chemotherapy, told me that she was found to have a tumour by the township hospital she lived in, which was one-hour driving time away. She was given the suggestion for surgery in the city hospital, and she went for treatment two months previously. She meant that she trusted professionals as she chose the hospital.

'I really don't know which doctor is good. But I come (and choose) here and I think I should believe in him.'

(Interview 0607, female, 32, rural resident, Breast and Thyroid Department, breast cancer, little education)

Following up the topic of trust, I asked them if they would like to ask their professionals to share decision-making, given they trusted them. Many responses thought that trust could lead to exclusion, as many regarded their professionals as the deputy in the process. For example, a man with intestinal obstruction felt he trusted this doctor, so he followed his recommendations.

'I prefer that my doctor makes most decisions for me, as I trust him—I believe he won't give me bad advice.'

(Interview 1403, male, 52, rural resident, Gastric and Intestine Department, acute condition, middle school education)

In contrast, some respondents talked about their feelings of distrust and dissatisfaction, which led to greater involvement. Due to a disagreement about treatments or lack of communication, some respondents had negative experiences and wanted to engage more with professionals. A man who disagreed with his professionals felt the relationship was 'so-so'. He came to the doctor and said what he felt about the proposal of treatments.

'I think the relationship is so-so. Well, it is normal to have different views of treatments. My doctor wants me to stay longer here, but I don't want to spend

more money. I came to his office and told him that I didn't accept it because of the cost.'

(Interview 0102, male, 52, urban employee, Cardiology Department, chronic condition, high school education)

Accordingly, I make the following tentative hypothesis: the more distrust patients have in professionals, the more likely they want to be involved in their health care.

6.3.2 The cultural context

In Chapter 2, I drew ideas from the theory of cultural capital (CC), which referred to the symbolic and informational resources affecting how people act; e.g. educational level; exposure to health knowledge; qualifications of health care. I attempt to examine how CC affects people's desire for involvement in health care delivery. In the interviews, I explore the concept of CC with three variables: education of patients; exposure to mass media; access and usage of the internet. I ask the following question in the interview: What is your educational qualification? How often do you read newspapers, books, or watch TV that are relevant to health issues? Are you able to use the internet? How often do you search the internet related to health and health care? Have you got any qualifications of health care?

I identify respondents with various levels of CC in the first stage of fieldwork. In particular, I categorise cases with rich CC, with average CC, and with poor CC, as defined below. I link the levels of CC to people's willingness for involvement in health care delivery.

6.3.2.1 Rich cultural capital

If the respondent has obtained a degree or certificate from college, AND he/she frequently gets information about health issues from mass media, such as newspapers, books and TV, AND he/she is able to search the

internet relevant to health issues, the respondent is categorised as a service user with rich CC. The example below shows an example of self-reported CC by a retired urban employer.

'I am a mathematics teacher. I graduated from a college. I often watch TV and read newspapers and magazines about health—almost every day. I use my smartphone to search the internet.'

(Interview 1105, male, 70, urban employee, Cardiology Department, chronic condition, well-educated)

6.3.2.2 Poor cultural capital

If the respondent has not received any education or had little schooling (e.g. primary schooling), AND he/she is not often exposed to mass media about health issues, AND he/she cannot access to the internet, the respondent has poor CC. Sampled cases with poor CC are far more numerous than those with rich CC. The example given below is the response from a woman from the rural area.

'I have some middle schooling, but just a few months. I only complete primary school. I don't read anything or watch TV about health. I am not able to use the internet—I cannot even send messages.'

(Interview 1003, female, 51, rural resident, breast cancer, primary school education)

6.3.2.3 Average cultural capital

Except for the respondents in the categories of rich CC and poor CC, the rest of respondents are categorised as having average CC. However, respondents with average CC demonstrate different features. Category 1 is the respondents who have a rather higher level of education (e.g. having obtained a qualification from the high school or the vocational school), but they rarely obtain health knowledge from mass media, books and the internet.

Some of them can use the internet, but most of them cannot. The example below is a retired teacher in a primary school. Although she does not have a degree from the university, she has a higher education compared to her generation.

'I taught in a primary school before I retired. I obtained a qualification from a teaching school. This is like a high school today. I don't often obtain health information from the TV and magazine. I can't use the internet. I don't really care about my health condition before I am ill.'

(Interview 0304, female, 67, urban employee, Cardiology Department, chronic condition, well-educated)

Category 2 are respondents who have a rather higher level of education (e.g. having obtained a qualification from the high school or the vocational education) and they often obtain health information from the mass media or books, but their information sources are nonselective. They cannot use the internet for health information. A respondent who had coronary heart disease for 25 years gave the following example.

'I graduate from a vocational school. I used to work in an industry. I don't watch TV or magazines. I only read instructions of medicine and sometimes books-books about coronary heart disease. I can't search the internet.'

(Interview 0506, male, 75, urban employee, Cardiology Department, chronic condition, well-educated)

Category 3 are respondents who have a lower level of education (i.e. middle school), and they often obtain health information from the mass media or books, but their sources of information are nonselective. Most of them could not use the internet for health information, as they lack the skills to search for the right information. A respondent who had coronary heart disease for over 20 years gave the following example.

'I retired from an industry in the city. I often watch TV and like health advertisements. I buy a lot of health care products from them. I think they are effective for my condition. I have a neighbour who does not buy any products. I think she is not as healthy as me...I can't use the internet.'

(Interview 1101, female, 71, urban employee, Cardiology Department, chronic condition, middle school education)

Category 4 is the respondents who have a rather low level of education (i.e. middle school), and they rarely obtain information from the mass media or books. Most of them cannot use the internet for health information. Here is the example of Category 4:

'I only have middle school. I seldom read or watch TV about health care. I watch TV for news more. I can't use the internet.'

(Interview 0902, male, 68, urban employee, acute condition, Gastric and Intestine Department, middle school education)

6.3.2.3 Cultural capital and involvement

Many respondents with rich CC mentioned '*information*' repeatedly, as they felt obtaining information was crucial. Some respondents said they sought information from various sources, such as TV, reading materials and the internet. It was evident that respondents with rich CC were capable of using the internet for information.

'I am an engineer and graduate from a college. I read relevant information and watch TV a lot, especially after I am ill. I search the internet every day, and I also keep an eye on similar medical cases in our country.'

(Interview 0104, male, 65, urban employee, acute condition, Emergency Department, well-educated)

'I am a doctor and I acquire qualifications from the college. I often search the internet for relevant information.'

(Interview 0907, male, 28, rural resident, acute condition, Gastric and Intestine Department, well-educated)

Almost all respondents with rich CC demonstrated a good understanding of their conditions and treatments. They said they fully understood what happened and what treatments they were having. The retired engineer told me that he was happy to know himself from tests and machines (e.g. Magnetic Resonance Imaging and Ultrasonic B). He wanted to compare statistics before and after the treatment.

However, this did not mean that respondents with rich CC liked to control the process of decision-making. Most respondents with rich CC showed little desire for shared decision-making: the majority of cases wanted more information and very few wanted exclusion. Only one case desired shared decision-making. When I asked why some respondents had little willingness for shared decision-making, a frequent response given was that they respected medical expertise and trusted in professional authority. Patients with rich CC revealed they did not want to challenge their professionals.

In contrast, many respondents with poor CC demonstrated more desire for an active role in health care decisions. A few cases said they wanted shared decision-making with professionals. Some argued that they had the right to know what was going on. Some wanted to have a trade-off and choose 'an effective treatment with less cost'. However, many patients with poor CC demonstrated their inability in obtaining or understanding information. Many told me that they were confused about test results and treatment recommendations. All of them could not access the internet, nor did most of them read intensively. It became one of the biggest barriers for communicating with professionals. It also led to exclusion in treatment decision-making. For example, an interviewee with some primary schooling told me that he felt he had to rely on professionals all the way.

Respondents with average CC demonstrated various demands for involvement. In Category 1, some respondents showed their willingness for information from health professionals, although they were mostly patients with chronic conditions and breast cancer. Some respondents in this category expressed their desire for shared decision-making, of which only two cases were with chronic conditions. In Category 2, there were only two cases in the category, and they both expressed their willingness for information, but they felt unwilling to be involved in decision-making. It seemed that patients with a higher educational level were not eager to make decisions, although they desired more information.

In Category 3, where respondents had a rather lower level of education but sought to obtain information from various sources, most cases demonstrated their willingness for information from health professionals or exclusion from decision-making. Although they showed their habit of seeking information from various sources, some said they felt difficult to make decisions. In Category 4, some cases demonstrated that they liked to share decision-making with professionals, although most of them were with acute conditions. This might be attributed to the degree of seriousness. Most of these patients felt the condition was not serious and were confident to be involved in the process. Yet, some cases said they only wanted information and some said they wanted exclusion from the decision-making process. It seemed that respondents with a lower level of education felt that the main obstacle for involvement was the lack of health literacy and knowledge.

From the analysis, it is not clear that patients in the average group want more or less involvement. Therefore, in this study I limit attention to those respondents with richer and poorer cultural capital, as defined above. The preceding analysis indicates two following tentative hypotheses: (i) Patients with rich cultural capital are more likely to want information than patients with poor cultural capital; (ii) Patients with poor cultural capital are more likely to want to be involved in decision-making than patients with rich cultural capital.

6.3.3 The social context

I explore two elements of the social context in the interviews: the family context and social capital. Some studies have explored the family's role in health care delivery, such as emotional support, information exchange and treatment decision-making (Laidsaar-Powell et al., 2016; Lee and Knobf, 2016). Active family involvement is essential in the Chinese context, which I confirm during fieldwork. Almost all respondents mentioned their families when they talked about decision-making. In the interviews, I asked specifically how family members were involved in decision-making stages (e.g. information exchange; treatment decision-making) and if they were happy with their family involvement.

Social capital (SC), referring to social resources patients and their families possess, is important in the Chinese context. Social resources in health care show how much help patients and their families are able to receive beyond formal service provision. Social networks in the health system that a patient and their family have often enable them to obtain useful information and confidence in making choices, as people trust someone they know with medical training and knowledge. I ask respondents if they (and their families) know someone in the health system and whether or not they contribute to their health care decisions. In addition, I consider patient networks as another type of social resources, as patients may get emotional support or other assistance from patient groups. I ask respondents if they are involved in patient networks (online or offline) and if it affects their desire for involvement in their health care.

6.3.3.1 Family and involvement

Some research mention the importance of family involvement in decision-making (Lee and Knobf, 2016). Many patients said 'we', when mentioning involvement. 'We' referred to their family and themselves. It seemed that the whole family, rather than the individual patient made decisions. This was also affected by disease-type. In the case of cancer, as mentioned in Section 6.2.1, the priority for communicating the results, if it was cancer, was not to the patient. Information was given to key family members first and then they

decided whether to tell patients or not. This may be due to psychological concerns, as patients were protected from negative news. This was particularly the case for the older patients, that family members (mainly children) took on the replacement role of information receiving and decision-making. In this context, it is important to explore the extent to which family members of patients are involved in treatment decision-making and if cancer patients are happy with family involvement.

Many patients described situations where families were involved in several stages of health care: information receiving; deliberation within the family; decision-making; post-treatment assistance. Many family members received information about the illness or condition from professionals. They also signed informed consent, replacing the role of patients. Family members provided emotional support and care before, during and after the treatment. Many patients said their family members deliberated with them about treatment options before they came to talk with professionals. Some family members participated in the discussion of treatment decision-making, along with the patients. They often shared decision-making together with professionals.

When asked about family influence over decision-making, younger and older patients said their family members (usually their parents or children) were controlling the process. They described situations where decisions were mostly shared between family members and professionals. Most respondents showed consent for the family dominance. Only a few older patients felt unhappy with it. They wanted to know more about what happened and expressed their preferences on treatment.

It seemed that middle-aged patients maintained the ownership of decision-making, compared to other age groups. Most male respondents said they deliberated with professionals and shared decision-making, without being greatly influenced by their family members. This behaviour might be related to their domestic roles because men tended to be more dominant over decisions in family life. A middle-aged man with a chronic condition told me that his condition was very serious. He found out that the treatment results

were not good and started to learn more about alternative treatments. Considering the costs of this treatment was an additional issue because he was also responsible to provide for this family.

In contrast, many women, especially those with a diagnosis of breast cancer, said their family involvement was greater. Family members mainly provided emotional support and information gathering. Many patients with breast cancer also appreciated family involvement in treatment decision-making. Older female patients, especially housewives, were keen to withdraw from decision-making and leave it to others, such as their children or spouses. A 46-year-old housewife from the rural area, mentioned that her daughter shared decision-making with professionals. She was stressed and wanted to give up treatment, but her daughter insisted that she had to accept treatment, seek information actively and make decisions with professionals. Some middle-aged women, despite more emotional support from their families, demonstrated an active role in treatment decision-making. A 40-year-old woman had to make choices between treatments. The professional recommended mastectomy, but she hoped she could conserve her breast. She told me she wanted to talk with her professional to discuss options.

Accordingly, I make the following tentative hypothesis: the middle-aged working patients are less likely to want family involvement in their health care than other groups.

6.3.3.2 Social capital and involvement

I ask two questions regarding SC: Is there anyone you or your family know working in the health system and offering help? Are you involved in some patient communities, or have you got in touch with other patients who have the same problem? Some interviewees told me that they had support beyond the core family when they were ill. Their family members or friends were working as professionals in the hospitals. They consulted with them and received reliable advice. They also contacted other patients with similar conditions, who they might know online or in the hospitals. However, a few

respondents said they knew no one in the system and they only consulted with their doctors. Some said their personalities were not open to share experience with others.

Like cultural capital, I categorise cases with different levels of SC. Some patients have a rich SC—they have support from families or friends who work in the health system. They are also involved in patient networks; e.g. joining patient groups online and offline.

'My daughter-in-law works in the medical college in the city, as a lecturer. She offers me a lot of advice. I often talk about it with other people I know in the ward, or in the neighbourhoods, as we have similar conditions.'

(Interview 0505, male, 70, urban employee, chronic condition, Cardiology Department, primary school education)

'My two sisters are working in the hospitals and give me a lot of advice. I often discuss with other patients about treatment schemes, outcomes and medications, both online and offline.'

(Interview 0104, male, 65, urban employee, acute condition, Emergency Department, well-educated)

It seems that many respondents with rich SC are not willing to share treatment decision-making with professionals. They are happier to rely on their social networks, who they think are more professional than themselves. This is particularly true when patients are elderly with rich social resources from the family. An old man who was 74 years old and whose four daughters were all doctors, left decisions to his children when he was accepting treatments for coronary heart disease. He told me that his condition was quite serious and had placed three vascular stents, but his daughters, who had a couple of doctor friends in the local hospital, discussed with professionals on behalf of his wife and himself. His daughters also covered part of the costs.

While many respondents relied on social networks from family members or friends, not many claimed they were involved in patient networks. For common problems, patients tended to learn from people they were familiar with, such as relatives, neighbours and patients in the same ward. Some respondents said they felt relaxed when talking to patients with the same or similar conditions. But networks seem to be casual and temporary.

For those conditions that were complex or uncommon, patients tended to get in touch online and maintained this relationship for mutual support and sharing information or experience. A middle-aged man with an unusual heart disease actively engaged with patients from other parts of the country. He told me that the disease was rare. He found it useful to talk to someone with the same condition. They shared details of treatments and life, trying to offer company for each other and providing information and emotional support. This relationship has been an important part of his daily life.

In terms of respondents with poor SC, I identified most cases with family support and very few cases without family support. For those with family support, many showed an unwillingness to discuss about their condition or illness with others. They had no additional social resource in the health system. A majority of the responses with family support liked more information from professionals. They did not feel the need to share their views with others and they chose to trust family members and professionals.

'My wife takes care of me...I don't talk to others, as everyone has a different condition. It is not helpful at all... I don't know anyone else in the hospital.'

(Interview 1501, male, 72, urban employee, acute condition, Emergency Department, primary schooling)

The respondents with no family support seemed to like engagement with professionals. The woman from a poor rural family told me that she had little support from her family. She had no relatives or friends working in the hospital. She did not want to talk to others about her condition, as her

personality was not open. She felt anxious to talk to her doctor, as she had no one else to learn about her condition and treatments. She complained that the doctor had not enough time to engage with her concerns.

'I take care of myself. I know no one in the system. I never discuss my condition with others, as I feel I don't want to share. But I do have a lot of questions to ask my doctor. For example, I wonder if I should place a stent in the vascular, as the vessel is blocked quite terribly. I also want to know more about my condition... My doctor should talk with me more. I saw him rarely.'

(Interview 0403, female, 53, rural resident, chronic condition, Cardiology Department, middle school education)

In terms of respondents with average SC, I identified and categorise two groups. Respondents in Category 1 were those who may have family support and support from social networks (i.e. their neighbours or patients). But they did not have connections to health systems.

'My daughter takes care of me...I don't know anyone else here. I don't consult with anyone, except for my doctor...But I talk to other patients. I feel much better when I talk to them.'

(Interview 1003, female, 51, rural resident, breast cancer, primary school education)

It seemed that the group of respondents showed various demands for involvement. The most frequent responses included information and shared decision-making. Unlike those who were not open to others, this group of respondents seemed to embrace communication beyond the family.

Meanwhile, respondents in Category 2, who had family support and connections to the health system (i.e. they have family members/relatives/friends who worked in the system with professional

advice and help), showed various demands for involvement due to their own condition. A case with breast cancer (interview 1004) liked to trust professionals and to withdraw from decision-making. The other case with breast cancer (interview 602) only wanted more information for illness management. The case with acute condition (interview 906) liked shared decision-making due to his preferences over treatment. However, it is not clear about the average groups and their willingness for involvement. Therefore, I only focus on respondents with richer social capital and respondents with poorer social capital.

Overall, I make the following tentative hypothesis: patients with poor social capital are more likely to want to be involved in their health care than patients with rich social capital.

6.4 Emergent hypotheses

Based on the evidence gathered in the first stage of fieldwork, I develop a series of emergent hypotheses, which will be tested and refined in the second stage of fieldwork.

H1: Patients with chronic conditions are more likely to want to be involved than patients with acute conditions.

H2: The later the stages of cancer, the more likely that patients are willing to be involved in their health care.

Perception of a not-serious condition:

H3a: Patients who are confident to talk with professionals, or perceived as educational, are more likely to want involvement.

H3b: Patients who trust professionals to act appropriately for their benefit are less likely to want involvement.

Perception of a serious condition:

H3c: Patients who believe that they have a personal responsibility (to get better) are more likely to want involvement.

H3d: Patients who perceive their condition as complex, leading to stress and incomprehension, are less likely to want involvement.

H4: The younger patients are, the more likely they want to be involved in their health care.

H5: Patients with RBMI are more likely to want to be involved than patients with UEBMI.

H6: The more distrust patients have in professionals, the more likely they want to be involved in their health care.

H7: Patients with rich cultural capital are more likely to want information than patients with poor cultural capital.

H8: Patients with poor cultural capital are more likely to want to be involved in decision-making than patients with rich cultural capital.

H9: Middle-aged working patients are less likely to want family involvement in their health care than other groups.

H10: Patients with poor social capital are more likely to want to be involved in their health care than patients with rich social capital.

6.5 Testing hypotheses

While drawing lay concepts and meanings from the first stage of fieldwork, I continue to use ARS to test and elaborate emergent hypotheses in the

second stage. Assumptions are tested deductively, based on the preliminary hypotheses drawn from the first stage.

6.5.1 The individual context

6.5.1.1 Type of disease

H1: Patients with chronic conditions are more likely to want to be involved than patients with acute conditions.

In the category of chronic conditions, I identify two types of SDM: type I that SDM is desirable among patients, family members and professionals; type II that SDM is desirable between family members and professionals. Many respondents who desired SDM claimed that they liked to know what was going on and expressed their preferences or concerns over treatment. However, the majority of respondents said that they wanted their families to deliberate and share decision-making with professionals.

In contrast, most patients with acute conditions expressed their unwillingness to be involved in decision-making. Many respondents revealed that they refused any information or involvement in decision-making. Some respondents claimed that they only wanted information from professionals.

The attribute of the disease has determined the opportunities for SDM. In the context of chronic condition, patients are given more time to deliberate and discuss choices they have encountered. For example, in the Cardiology Department, many patients with diagnoses of vascular occlusion (over 70%) are faced with treatment options, whether to place vascular stents or not or the choice of an angiogram. Most patients are given information about their condition (e.g. to what extent the vascular artery is blocked; if it is serious enough to do an angiogram) and choice of treatments. Some respondents are concerned about adverse effects of an angiogram, while others care about costs. Many feel the need to seek information and to deliberate with professionals. A patient's son told me that he did not trust an angiogram and

requested an alternative examination. Together with his father, he wanted to talk to the doctor about their concerns.

'I feel I do not want my father to do the angiogram, as I want to know the extent the blood vessel is blocked and if it can be seen from the ultrasound. I am very worried about the side effects of angiogram. We need to discuss with the doctor, as I am not clear about the negative part of angiogram.'

(Son of the patient, interview 102, chronic condition, Case 1, Cardiology Department)

Unlike chronic conditions, many patients with acute condition have no opportunities for sharing decision-making. Patients who had accidents told me that it was an emergency situation. There were not many things that their family and themselves could do.

'It is an emergency and it happens suddenly. I think I was very unconscious and I had to hand myself over to the doctor.'

(Interview 403, male, 48, acute condition, Case 1, Emergency Department, rural resident)

'I felt it was very terrible, but I had to listen to my doctor. It was an emergency and my parents were also in a panic and did not know what to do. You see, it was the doctor who made the decisions.'

(Interview 404, male, 28, acute condition, Case 1, Emergency Department, rural resident)

Due to the long-term experience of coping with the disease, patients with chronic conditions were more aware of the responsibilities for illness management. They were aware of their medication and how to control their conditions.

'It is a lifelong condition and I feel I need to know everything and learn how to control it myself. I can understand the use of medicine now, for example, aspirin, which is for prevention of causing thrombus. So yes, it is my own responsibility.'

(Interview 118, male, 57, chronic condition, Case 2, Cardiology Department, urban employee)

Many respondents with acute conditions thought they had the rights to know their condition and treatment plans, as they believed that professionals should make decisions. A respondent who had a bone fracture told me that he liked to follow the advice of professionals, although he had the right to receive information and to make his own choices.

'I tend to follow my doctor mostly. He is professional, so I need to follow his advice. I do have my own concerns. But I think professionals are responsible for advice, while patients have rights of knowing everything and making choices.'

(Interview 412, male, 40, acute condition, Case 2, Emergency Department, urban employee)

Another respondent, who had an operation for acute appendicitis, demonstrated that obtaining information was more important and necessary.

'Yes, we have to follow professionals, but I do have some requests. I feel I need to learn more about the disease and post-operation instructions. I may buy some books about it.'

(Interview 301, female, 68, acute condition, Case 1, Gastric and Intestine Department, urban employee)

Therefore, there is no evidence here to reject H1. It makes clearer that patients with chronic conditions are more likely to want to be involved than patients with acute conditions.

6.5.1.2 Cancer

H2: The later the stages of cancer, the more likely that patients are willing to be involved in their health care.

To explore associations between stages of cancer and desire for involvement, I sampled patients at various stages of treatments. There are 13 interview respondents with new diagnoses of breast cancer, having encountered the decision of BCT or mastectomy. They told me that they had to choose between chemotherapy and radiotherapy. In addition, two cases were in the stage of post-chemotherapy, facing treatment with hormone therapy. They had discussions with professionals about medications. Two cases were in the middle or late periods of cancer, having been found with metastasis. They were taking chemotherapy again.

Many patients with newly diagnosed breast cancer said they did not want to make decisions, although some of them said they wanted information about the stages and their chances of survival. Most of the respondents who desired no decision-making were younger or older patients.²⁰ They felt stressed and lacked confidence to engage with professionals.

Three patients with new diagnoses of cancer said they desired autonomy over decisions. They were all women who were working or had worked for years. For example, a 52-year-old woman who was working in the public sector identified the tumor herself and insisted on going to the hospital. She said she felt the responsibility to take on her health care and should be involved in the decision-making process.

Another woman claimed that she was prepared to accept negative news from professionals.

²⁰ Two cases were below 30 years and 4 cases were over 50 years old.

'I think my condition is not the worst. The operation is simple. I am happy to discuss with my doctor about treatments. I feel like knowing more about my conditions. I also told my doctor before the operation that I prefer to a minimally invasive surgery.'

(Interview 212, female, 61, breast cancer, Case 2, Breast and Thyroid Department, urban employee)

Two patients with new diagnoses of breast cancer said they requested SDM between their families and professionals. With a low level of health literacy, they handed it over to their children. Different from exclusion, they wanted their families to know what happened and to share decision-making with professionals. A special case was of an elderly respondent who preferred to be more involved complained that she felt unhappy of being excluded by professionals and her families.

In general, most respondents who were in the early stages of treatment preferred to be less involved in the process. Reasons for little involvement included perceptions of incompetence in SDM; psychological stress; trust in professionals.

Patients who have had chemotherapy or radiotherapy preferred to share decision-making. They said they were able to be more confident during these post-operation stages because they were more knowledgeable about the disease. All of them actively sought information about treatments and they were happy to share their feelings with others. A 38-year-old patient told me that she had just had the operation. Her professional came up and said: 'You knew your condition and it was not serious. But you should have chemotherapy for four courses.' She told the doctor that she agreed to have chemotherapy, but she wanted to make sure the dosage was not strong. She also wanted to know what medication she would receive.

'I want to know more. I have many concerns, as I draw ideas from others and want to ask my doctor if I can do this.'

(Interview 217, female, 38, breast cancer, Case 2, Breast and Thyroid Department, urban employee)

Although chemotherapy or radiotherapy was difficult to endure, two respondents had survived cancer and received medication. They were optimistic and happy with their treatment outcomes. They claimed that they were very keen to obtain information and SDM. A respondent with the diagnosis of cancer for three years said she was very dependent on her professional. Later, she regretted that she did not tell the doctor her preferences. She would have chosen BCT if time could go backwards.

'I was totally shocked when I knew it. I really knew nothing about it. It was all decided by the doctor. The doctor asked me if I would like to maintain the breast. I had no idea and I asked the doctor to make decisions. If it had happened now, I think I will definitely share decision-making, as I suffer from the mastectomy.'

(Interview 221, female, 54, breast cancer, Case 3, Breast and Thyroid Department, urban employee)

She also mentioned she created an online patient network in the local hospital, and organised outdoor activities for the group. She was very focused on the latest technologies and frequently offered advice to other patients.

Another respondent, who was having chemotherapy for the last treatment, mentioned that she was very willing to obtain scientific knowledge about the illness. Physically, she felt much better, compared to her previous chemotherapy. She also became more confident to discuss treatments. Another respondent also mentioned that she was involved in patient networks to share information and experience.

Patients are diagnosed with middle or late stages of cancer are more likely

to exclude themselves from health care delivery. Neither of the two respondents with cancer metastasis sought to be involved in decision-making. A patient in the middle stage of cancer said she and her family would trust her doctor, as they went to the best hospital in the province. She was told she needed to have eight courses of treatments, and she did not say anything about it. She told me, 'I don't doubt their authority and decisions.'

A rural woman whose cancer had spread to her lung, was very pessimistic and refused to receive any information from professionals. Her daughter thought it was better to rely on professionals, as they had no idea what to do next.

'The doctor made a chemotherapy plan. And we followed it. That is the only thing we know.'

(The daughter of the interviewee, interview 224, female, breast cancer, Case 3, Breast and Thyroid Department)

Although some evidence suggests that in the later stages of cancer it is, the more likely patients are willing to be involved in their health care, more evidence here suggests rejecting H2, as patients in the middle or late stage of breast cancer may not want involvement due to the seriousness of condition, which lead to stress and incomprehension.

6.5.1.3 Seriousness of condition

Perception of a non-serious condition:

H3a: Patients who are confident to talk with professionals, or perceived it as educational, are more likely to want involvement

H3b: Patients who trust professionals to act appropriately for their benefit are less likely to want involvement.

Perception of a non-serious condition:

H3c: Patients who believe that they have a personal responsibility (to get better) are more likely to want involvement

H3d: Patients who perceive their condition as complex, leading to stress and incomprehension, are less likely to want involvement.

I start by analysing the group of patients with acute conditions. The majority of respondents said they felt the conditions were not serious, and some respondents perceived their conditions to be very serious. Most respondents who perceived their conditions to be not serious said they wanted to exclude themselves from decision-making. They mentioned that they did not have the capacity to engage, that their illness was not serious, or that they felt too old to make decisions. Among the cases who perceived the condition serious, more respondents preferred exclusion, as they said the condition was too serious to make any decisions (interview 314, 403 and 404). But there are cases who want more involvement. One respondent preferred shared decision-making, as he needed to consider costs and had a clear idea about treatment he needed (interview 413). One respondent wanted information, as he believed he had right to choose (interview 412).

I then looked at cases within the group of chronic conditions. Most patients described their conditions as not serious. Most of them claimed that they liked shared decision-making and two respondents said they wanted information. Their reasons for engagement included preferences over treatments, concerns over costs, right of information and responsibility for health care. But there are two cases showing little desire for any involvement, as they did not have much confidence to engage with professionals. However, some respondents felt that their condition was serious, as many of them had blocked blood vessels. Two respondents (interview 122 and 121) wanted information, because they wanted to understand the treatment process. Some respondents (interview 113, 102, 103 and 118) said they liked to share decision-making. They needed to know how the situation was and wanted to weight their options. A man who was found to have three places of vascular blockage was told that he was in a dangerous condition. He deliberated with professionals as he did not want to have a heart by-pass, which was

recommended by his professionals.

'I need to have a discussion with my doctor. There are three places of vascular blockage. One of them is totally occluded. They say the only approach is a heart by-pass. But I want to do vascular stents. I think we should discuss further and I like to share decision-making.'

(Interview 113, male, 59, chronic condition, Case 2, Cardiology Department, rural resident)

In the group that perceived their condition as not serious, there is no evidence in this stage that makes it clear that having confidence to talk with professionals leads to them more likely to want involvement. So H3a is rejected. This could be further tested through other approaches, such as quantitative surveys. However, there is no evidence to reject H3b, as some new evidence shows that trust in professionals to act appropriately does reduce the likelihood of wanting involvement.

In the group that perceived their condition as serious, there is no evidence here to reject H3c. It makes clearer that patients with a sense of personal responsibility to get better are more likely to want involvement. Moreover, there is no evidence here either to reject H3d. It becomes clearer that perception of complexity leading to stress and incomprehension leads to less likelihood of wanting to be involved.

The data analysis in the second stage also indicates that while seriousness of condition is important to understand the willingness for involvement, there are other factors that need to be taken into account, such as age, cultural capital, health insurance type and disease-type. In other words, there is an interaction effect in evidence.

6.5.1.4 Age

H4: The younger patients are, the more likely they want to be involved in their health care.

Age seems to be a determining factor that affects people's willingness for involvement, regardless of disease-type. Older patients with chronic conditions tended to leave decisions to other people and some preferred to be totally excluded from decision-making. Others wanted their family members to share decision-making with professionals. Two respondents with chronic conditions, who were 68 and 78, respectively, said they only wanted information. One respondent who was 61 years old preferred to be completely excluded from the process. In situations where decisions needed to be shared, many elderly patients tended to leave it to others. Seven respondents, whose age was between 57 and 78 years old, said their children would talk to professionals.

A 62-year-old woman with vascular blockage told me that she felt too old to think about the disease. She felt stressed when she was informed about her condition, although it was not serious at all. When I asked her if she wanted to manage the illness in the long run, she said yes. But her daughter would do it for her. Her daughter supplemented what had happened,

'I asked the doctor and nurses about the conditions. I also searched the internet to know more about my mother's problems and treatments. I talked with the doctor about treatment plans, as my mother did not want to be involved in the discussion. I think it is my responsibility to do it.'

(Patient's daughter, interview 111, female, chronic condition, Case 2, Cardiology Department)

In the group of acute conditions, a majority of respondents were above 55 years old. Among them, some respondents said they wanted to be excluded, or receive information without being involved in the decision-making; one

patient said he wanted his children to share decision-making with professionals. The interviewed respondents repeatedly mentioned their children, who took care of them and obtained information about their condition. Their children, rather than they signed the informed consent form.

For example, a 67-year-old man who had ileus told me that professionals asked his children for informed consent. They also knew his condition and he did not want any information at all.

'The doctor told my children everything and asked their consent. He did not ask me. I would rather the doctor made decisions, as I trusted him. But I do want to know more about the condition and post-operation items.'

(Interview 401, male, 65, acute condition, Case 1, Emergency Department, urban employee)

Another 76-year-old man, who had the ileus, said he just had the operation four days ago. But he did not know anything about his condition, as his son took care of him and told him what to do. He said he did not want to ask actively because he trusted the doctor and his son.

'Yes, I totally follow the doctor's instruction. I did not feel like asking too much...The operation is over and I think my son will tell me what to do next.'

(Interview 313, male, 76, acute condition, Case 2, Gastric and Intestine Department, rural resident)

In contrast to elderly patients, most younger patients preferred an active role in decision-making. Not only did they seek information from various sources, they were also more willing to know why they had to take examinations or treatments. One of the young patients, who was 34 years old with the diagnosis of the coronary heart problem, told me that he wanted to know the objectives of every test or examination.

'I feel that I need to have my own idea and I prefer to share decision-making. They also need to obtain my consent if they conduct any tests or examinations, as I need to know why I have to do this.'

(Interview 105, male, 34, chronic condition, Case 1, Cardiology Department, rural resident)

Some patients with chronic conditions revealed that they were aware of their responsibility to maintain health, as they wanted to work and live for many years. This was probably why they were motivated to get involved.

Therefore, there is no evidence here to reject H4. It makes clearer that the younger patients are, the more likely they want to be involved in their health care.

6.5.1.5 Health insurance type

H5: Patients with RBMI are more likely to want to be involved than patients with UEBMI.

The motivations mentioned by the sampled respondents with chronic conditions included treatment preferences, rights to know the conditions, distrust in professionals, responsibility for health care, costs, concerns over adverse effects. Although costs were not the most frequent response, the two responses were from RBMI users. Many told me that they were given more than one treatment with different prices when options were discussed. For example, patients with the diagnosis of vascular blockage were given two kinds of stents: one was made in China, costing around 6000 yuan (around 671 pounds), while the other one was imported and came at a cost of around 10000 yuan (around 1119 pounds). In contrast, UEBMI users were not required to consider costs to the same extent. as over 70% payment was covered by the insurance. Government employees could get 100% refund with the insurance. However, RBMI users were not so lucky, as only 50% payment was covered. Thus, the two respondents who came across options

mentioned that one of the motivations for getting involved was to deliberate with professionals, as they wanted to choose a cheaper treatment.

'I think I need to share decision-making, as I have to consider the cost.'

(Interview 104, male, 67, chronic condition, Case 1, Cardiology Department, rural resident)

No UEBMI users mentioned costs. They were concerned about treatment outcomes and negative effects of medication or examinations. For example, a woman who was a retired public servant talked about her willingness to engage with professionals. She was newly diagnosed with coronary heart disease and she engaged with the professionals actively. She also asked a second opinion for treatment.

'I like to control my own conditions. I think it is great to share decision-making with professionals, as we can achieve agreements. I also consult with other professionals in other hospitals, as I can know different viewpoints. In the end, I can find the best treatment plan. I don't need to consider costs, as the insurance covers everything.'

(Interview 117, female, 69, chronic condition, Case 2, Cardiology Department, urban employee)

In the group of acute conditions, although the majority of respondents preferred not to engage or receive information, a special case was a patient from the rural area who broke his bones. When the professional told him that the best treatment was surgery, he was very reluctant and kept asking if he had to do it. He told me that the surgery was too expensive, and he wanted to ask his doctor if they had cheaper options.

'I need to share decision-making. I don't really want surgery. It is too expensive. I just want to have pills, which may be a conservative treatment.'

(Interview 414, male, 56, acute condition, Case 2, Emergency Department,

rural resident)

Patients with breast cancer rarely mentioned costs as a driver behind their involvement. Most of them mentioned treatment preferences, responsibility for health care, right to know the condition, distrust and desire for well-being as their main motivation for SDM. A UEBMI patient in the stage of chemotherapy demonstrated that she thought treatment outcomes were much more important than costs.

'I think it was the treatment outcomes I considered when I made choices. Compared to the treatment with lower costs, I would choose a better treatment that costs more, as the outcomes are supposed to be better.'

(Interview 203, female, 39, breast cancer, Case 1, Breast and Thyroid Department, urban employee)

A patient with breast cancer, who preferred to receive information without being involved in decision-making mentioned costs. She was a RBMI user. She said she followed the recommendation, but she would disagree if her doctor gave her an expensive prescription because she needed to consider costs.

Overall, there is no evidence here to reject H5. It makes clearer that patients with RBMI are more likely to want to be involved than patients with UEBMI.

6.5.1.6 Doctor-patient relationship

H6: The more distrust patients have in professionals, the more likely they want to be involved in their health care.

Most respondents claimed that they had a trusty relationship, regardless of disease-type. When talking about trust, they also meant 'dependency'. They

explained that they trusted professionals and they relied on them in decision-making. The main reason for 'dependency', given by respondents, was the lack of health knowledge or experience. A woman with a chronic condition was passive in her health care, as she trusted her doctor.

'I prefer not to make decisions myself. I like the doctor to make decisions for me. I don't really feel like knowing more about the condition.'

(Interview 101, female, 52, chronic condition, Case 1, Cardiology Department, rural resident)

A woman in the middle stage of breast cancer also said that she trusted her professionals because they enjoyed a good reputation in the region.

'I totally trust professionals. No one in the family is involved in the process. I had the operation in Jinan, the capital city of the province. I trust their expertise in the hospital, as it is supposed to be the best in the region...I prefer to rely on my doctors, as I really trust them.'

(Interview 223, female, 34, breast cancer, Case 3, Breast and Thyroid Department, rural resident)

A patient with acute conditions also expressed the desire for exclusion because he trusted his doctor.

'Both my son and I had to listen to the professionals, as we knew nothing at all.'

(Interview 321, male, 71, acute condition, Case 3, Gastric and Intestine Department, urban employee)

Some respondents, regardless of disease-type, claimed that they did not trust their professionals. Notably, the majority of cases mentioned that they wished to share decision-making due to distrust and dissatisfaction with the

professionals. Some wanted to know more about specific aspects, such as tests, examinations and costs. Many respondents demonstrated that they needed to check service items when leaving the hospital. They also asked professionals why they charged for some services.

Some respondents were not convinced by treatment plans professionals offered. Many requested information from various sources, such as personal experience. A 92-year-old man told me that he had experienced diagnostic errors, which had a negative impact on his trust in what doctors told him.

'I trust other people's experience. Advice from professionals is only part of my consideration.'

(Interview 123, male, 92, chronic condition, Case 3, Cardiology Department, urban employee)

Another respondent also had a negative health care experience, which became the main cause of distrust. She relied on herself for information. She told me it was necessary to share decision-making with professionals, as it could avoid diagnostic errors.

'I did an annual health examination a month ago. They did not find the tumor. I was very surprised at it, as I found it myself. I checked again and went to the hospital myself.'

(Interview 204, female, 52, breast cancer, Case 1, Breast and Thyroid Department, urban employee)

Overall, there is no evidence here to reject H6. It makes clearer that patients are more likely to demand involvement with professionals when they feel less trust in them.

6.5.2 The cultural context

H7: Patients with rich cultural capital are more likely to want information than patients with poor cultural capital.

H8: Patients with poor cultural capital are more likely to want to be involved in decision-making than patients with cultural capital.

Compared to professionals who were well-trained and obtained a qualification in the formal educational institutions, most patients thought they had 'little health literacy'. Even though some service users were highly educated, no one regarded themselves as an expert in health care. That was why not many cases were identified as users with rich CC, who had obtained a qualification of higher education and had the competence in obtaining and understanding health-related information from various sources.

I identified some cases with rich CC: three cases with a chronic condition and two with an acute condition. All respondents with rich CC were urban employees who worked for the public or private sectors. All respondents claimed that they were active in seeking information from various sources, including reading material, TV and the internet. When asked about their preferences for information types, most respondents said that they liked general facts from professionals or scientific materials more than personal experience or mass media. They thought personal experience and news from TV or newspapers were not reliable. They also selected information on their own. For example, a man with the diagnosis of coronary heart disease told me that he mainly asked professionals for information or read science articles.

'I tend to know facts from doctors and nurses. I am really doubtful about information on the internet, as everyone has a say.'

(Interview 121, male, 48, chronic condition, Case 3, Cardiology Department, urban employee)

The man, having stents implanted for over ten years, said that he read instructions about medicine and asked for the professionals' viewpoints.

'I think I will listen to the advice from professionals. I can obtain information from all sources, such as the internet and personal experience. But I only believe in what my doctor says.'

(Interview 118, male, 57, chronic condition, Case 2, Cardiology Department, urban employee)

However, most cases said that they did not like to be involved in health care decisions, although they wanted as much information as possible. 'Trust in authority' was frequently mentioned when patients explained why they preferred less involvement. For example, a man who broke his bones told me that he looked up his tests and examinations on the internet because he was not familiar with the medical terms. But he relied on his doctors and nurses when he had the accident because he felt they were more professional.

'I liked to search the internet about everything. I learnt medical terms from my test results. The doctor was too busy to engage with everyone. I could not ask every detail. I asked some doctors online or searched it myself. I also searched cure rates and post-surgery risks. But if you say decision-making, I think professionals are experts and there is no doubt that I need to trust them. Their information is more reliable.'

(Interview 412, male, 40, acute condition, Case 2, Emergency Department, urban employee)

This behaviour stands in contrast to responses of patients with poor CC. In the group of patients with chronic conditions, all respondents preferred SDM, although some patients wanted their family to share decision-making with professionals (interview 114, 103, 111 and 112). Those respondents were

older and unemployed rural residents. They were illiterate and unable to use the internet. They also showed little experience in obtaining health knowledge, as they had little education. These patients demonstrated that they were not equipped to be involved in decision-making, but they wanted their family to be involved in the process.

'I have placed two stents, as I was diagnosed with coronary heart disease... I did a lot of farm work, so I really had no time to care about health... I had some primary schooling and could not use the internet. I think I know little to engage with the doctor. But I hope my families can discuss with the doctor and they actually do.'

(Interview 114, male, 67, chronic condition, Case 2, Cardiology Department, rural resident)

In the group of breast cancer patients, I identified some cases with poor CC. Similar to the respondents with chronic conditions, they were older and unemployed rural residents. One respondent (interview 206), who felt she and her family knew not much of health care, insisted that they did not want to engage with professionals and to share decision-making. Another respondent (interview 208) refused to engage with professionals but wanted to receive more information, especially about the price of medicine and treatment. The other two cases (interview 218 and 205) preferred shared decision-making because they wanted to favour a certain treatment and increase their ability to manage the illness.

I identified some respondents with acute conditions in the category of poor CC. Most of the respondents were rural residents with little education. Three cases (interview 303, 322 and 402) showed their desire for no involvement, two of which were old people. One respondent (interview 414) from the rural area said he liked to share decision-making with his doctor, as he had preferences over treatment. The two other cases (interview 422 and 301) wanted more information for disease management because they were aware that the disease might affect their life for a while.

'I got injury when I had farm work...It was not serious but it might take a while to recover...I wanted to know more from the doctor and nurses. What happened if I got anemia and osteoporosis? Could someone tell me these things?'

(Interview 422, female, 63, acute condition, Case 3, Emergency Department, rural resident)

Respondents within the four categories of average CC demonstrated various demands for involvement. In Category 1, two respondents (interview 102 and 115) with chronic conditions liked shared decision-making and one respondent (interview 124) wanted exclusion; one respondent (interview 202) with breast cancer wanted shared decision-making and the other two respondents (interview 207 and 213) wanted information; no respondents with acute condition were identified in this category. Most of the respondents who liked shared decision-making and information felt the need to get involved and know their own condition, as it affected their life quality. In Category 2, all the three respondents (interview 107, 116 and 117) with chronic conditions, who had a rather higher level of education but not selective of information, liked to share decision-making. Some patients (interview 204, 203, 201 and 212) with breast cancer preferred shared decision-making. Two respondents with breast cancer (interview 214 and 215) wanted information and three respondents (interview 222, 223 and 221) desired for exclusion. One respondent with acute conditions wanted information. It seemed that in Category 1 and Category 2 patients with a higher level of education were not necessarily unwilling to share decision-making, but information seemed to be essential for most of them. It also showed that many respondents with chronic conditions and breast cancer liked to be involved in decision-making. Other factors, such as type of disease, stage of treatment and seriousness of illness, were likely to have an impact on the willingness for involvement.

In Category 3, one respondent (interview 123) with chronic conditions liked shared decision-making, while the other one (interview 122) only wanted information. Another respondent (interview 211) with breast cancer wanted information and the other respondent (interview 216) liked to be excluded

from decision-making process. One respondent (interview 312 and 304) with acute conditions liked information and the other respondent (interview 302) liked exclusion. In this category, some respondents claimed that they wanted some information, as they felt information was important. In Category 4, one respondent (interview 101) with chronic conditions wished to be involved in decision-making, while the other one (interview 113) wanted information. One respondent (interview 217) with breast cancer wanted shared decision-making and the other one (interview 224) wanted exclusion. Moreover, some respondents (interview 314, 311, 313 and 321) with acute conditions liked to be excluded from decision-making. In this category, some respondents, who had a rather lower education and did not obtain information in health care, claimed that they wanted exclusion in health care decisions. This was because they were not confident with their health knowledge. However, in the group of average CC, the evidence does not make it clearer about the willingness for involvement. Therefore, I only compare groups with rich cultural capital with groups with poor cultural capital.

There is no evidence here to reject either H7 or H8. It is clearer that patients with rich cultural capital are more likely to want information than patients with poor cultural capital. It is also clearer that patients with poor cultural capital are more likely to want decision-making than patients with rich cultural capital.

6.5.3 The social context

H9: The middle-aged working patients are less likely to want family involvement in their health care than other groups.

H10: Patients with poorer social capital are more likely to want to be involved in their health care than patients with rich social capital.

6.5.3.1 Family and involvement

The family context is an important factor that affects people's willingness to get involved in health care. In the fieldwork at the second stage, almost all

respondents mentioned their families. While a small number of patients mentioned that their role was replaced by their family in health care, the majority referred to the supplementary role of information gathering and decision-making. Some respondents felt it was important to involve family members because their lives were affected by the illness. A woman with breast cancer (interview 202) illustrated that she felt her illness was not only her individual concern, but an important matter for the whole family. Some family members, who were involved in the interviews, said that they felt obliged to be involved in the process, including care, decision-making and emotional support.

While most respondents illustrated their preferences for SDM with family members, some said their family controlled the process. Some respondents told me that they were happy with family dominance. They were mainly older patients who were retired or unemployed, or very young patients (e.g. two female patients with breast cancer). An important reason for family dominance was patients' non-decision-making role in the family. For example, a 78-year-old retired teacher, with the diagnosis of coronary heart disease for 6 years, told me that she rarely engaged with professionals and her daughter took on this role.

'I am retired and I do nothing for living now. My husband and I are both ill. We are taken care of by our children. I have been diagnosed with coronary heart disease for 6 years. The professional shared decision-making with my daughter, not me nor my husband. My daughter knew a lot about the disease and I was not really involved in it. She told me how to take care of myself and what pills to take every day.'

(Interview 107, female, 78, chronic condition, Case 1, Cardiology Department, urban employee, retired)

The other important reason of family involvement was that many families were paying for their health care spending, especially for those patients who were unemployed. This may lead to them being excluded from the process, as they felt they were in a position to make decisions. For example, a

rural housewife who was 52 years old told me that she preferred to withdraw from making decisions, although she was involved in decision-making.

'I don't work and I help with looking after my grandchildren. I have been ill for 1 year. My children take care of me when I am in hospital. They also pay for treatments, as I have no pension at all. When I had an operation 1 year ago, I discussed with them together, including my doctor and the children. I would rather others make decisions. But my children felt that I needed to know my condition, so I was involved in it.'

(Interview 101, female, 52, chronic condition, Case 1, Cardiology Department, rural resident, unemployed)

Most respondents were happy with family arrangements in health care but two patients (one with a chronic condition and one with breast cancer) told me that they wanted to be more autonomous. One patient, newly diagnosed with coronary heart disease, said he wanted to be more involved, although his son shared decision-making with professionals. The other patient, also newly diagnosed with breast cancer, complained that she was excluded from everything. She wished to know more and to choose treatments herself.

'I wish I could be involved in decision-making, as I wanted to know more about my condition. I also felt I need to be involved, as it was my health.'

(Interview 106, male, 64, chronic condition, Case 1, Cardiology Department, urban employee)

'I want to control it. If the condition is very serious, I want to know as much as I can. But I am excluded from the process, as my family and doctors are discussing my treatment.'

(Interview 201, female, 62, breast cancer, Case 1, Breast and Thyroid Department, urban employee)

It seemed that middle-aged patients and the employed had more autonomy

over decision-making. On the one hand, they were more confident or competent to engage with professionals. Most employed patients were more educated. On the other hand, they were playing roles of decision-making in the family. For example, the 38-year-old woman, who was diagnosed with breast cancer a week before the interview, had been working to support her family and told me that she shared decision-making with professionals, although her sisters were taking care of her.

'I am working to support my family. Although my sisters take care of me, I have to make decisions on my own, with my doctor. I am told cancer by him.'

(Interview 217, female, 38, breast cancer, Case 2, Breast and Thyroid Department, rural resident, working)

Another respondent, although retired, told me that he preferred to share decision-making. This was mainly due to his role as decision-maker in the family and the consideration of costs.

'I am still working in the village. My wife takes care of me when I am ill. But I am the one to make decisions at home... I think decisions should be made with doctors together, as I am concerned about cost. I need to know what I have to pay.'

(Interview 104, male, 67, chronic condition, Case 1, Cardiology Department, rural resident, working)

Overall, there is no evidence here to reject H9. It is clearer that middle-aged working patients are less likely to want family involvement in their health care than other groups.

6.5.3.2 Social capital and involvement

Compared to CC, SC was not often mentioned by respondents, unless being asked by the interviewer. In the group with chronic conditions, all patients

with rich SC claimed that they preferred SDM, although one respondent only wanted information (interview 122). Having been managing the illness for a long time, respondents have obtained rich social resources. They also showed a strong interest in developing social networks, such as patient groups. A man with the diagnosis of coronary heart disease for over 40 years told me that he established a patient group and shared his experience of illness management.

'I have been coping with the condition for more than 40 years. I knew doctors in the department well, but I didn't follow their advice. I also tried to persuade them that my ways were more effective. They asked me to stop alcohol, but I told them that it was good for health to drink a little bit every day. I had a group of friends who had the similar conditions, and we shared experience every week. We organised to read health magazines and exercise together. I would like to trust people's experience and consider advice from doctors partially. I also need to discuss with doctors equally.'

(Interview 123, male, 92, chronic condition, Case 3, Cardiology Department, urban employee)

However, desire for involvement was not the same with breast cancer patients: two respondents preferred to share decision-making with professionals; one respondent wished that her family could share decision-making with her; one respondent only wanted information; one patient said she preferred paternalistic decision-making. Likewise, the respondents who preferred to share decision-making told me that they developed patient networks and found it beneficial.

'We have a Weichat group and it is very lovely. I meet many friends who have breast cancer. We like to share experience. We often go to the hospital in the group, as it helps with stress relief.'

(Interview 221, female, 54, breast cancer, Case 3, Breast and Thyroid Department, urban employee)

Yet, the respondents who did not like SDM told me that they trusted the professionals and their families. Two respondents (interview 222 and 214) knew the doctors well and have been friends for years. Another respondent (interview 216) relied more on her family member, who was working in the hospital.

'I told my doctor that he could make decisions alone. I felt trust with him, as we had been friends for years.'

(Interview 222, female, 50, breast cancer, Case 3, Breast and Thyroid Department, urban employee)

In the group with acute conditions, two respondents with rich SC mentioned that they wanted their professionals to make decisions, although they were keen on more information. One patient (interview 412) had family members who were working as health professionals. He said they had deep networks in the hospital. He could always consult with someone who was more professional than he was. The other patient (interview 421) also mentioned trust in the professional, who was her relative working in the same hospital, who offered advice for recovery.

It seemed that the demand for involvement was also varying among patients with poor SC. There were quite a few cases with poor SC in the interviews. Two respondents (interview 103 and 414) had no family support and other social networks. The rest received support from their family. Two respondents with a chronic condition preferred paternalist decision-making; the other four respondents liked SDM. Two respondents with breast cancer were keen on information without decision-making, while one respondent liked SDM. Two patients with an acute condition desired SDM; the rest of the cases preferred less involvement.

For patients who preferred SDM, uncertainty might be a motivation for engagement. A respondent, who had an accident, mentioned that he had a preferred treatment while the professional gave him two options. He

discussed with everyone, including professionals and his family.

'The doctor said there were two plans: one was a surgery and the other was natural recovery. I like to recover naturally. But I learn from him that there was a risk of joint conglutination. I am totally tangled, and I discuss with my family and the professional again.'

(Interview 413, male, 61, acute condition, Case 2, Cardiology Department, rural resident)

Those respondents who were not keen on involvement, regardless of disease-type, tended to trust professionals, which was repeatedly mentioned in the conversation. However, they meant they 'had to trust' as there was no other resource to use. A quite young woman (interview 207), a university student from a rural family, was diagnosed with breast cancer in the early stage. Her family supported her and she was not mature enough to make decisions. Her mother said her situation was special, as she was too young. Her parents were both rural residents without rich SC—they had no social network in the local hospital. They told me that they had to rely on the doctors, as no one else could offer advice. Meanwhile, they were less likely to discuss her illness with other non-professionals, compared to those with rich SC. Many respondents said they were not willing to speak with others as they felt 'useless'. They also hardly mentioned anything about patient networks.

In terms of average SC, respondents in Category 1, who claimed that they liked to share with other patients with similar experience, showed different demand for involvement. Some respondents liked shared decision-making, and they were all with chronic conditions or breast cancer. Some respondents only wanted information, with three having breast cancer and one with an acute condition. Some respondents said they liked to be excluded from decision-making, of which three patients with acute conditions. In this category, patients with chronic conditions and breast cancer were more likely to be more involved in the process due to the need for illness management and preferences over treatment. The two respondents with breast cancer (interview 223 and 224) preferred exclusion from decision-

making due to the seriousness of illness. The three respondents with acute conditions (interview 314, 322 and 403) liked paternalism, as the conditions were emergency. Accordingly, it seemed that it did not necessarily lead to the embrace of involvement for those who were more willing to share experience with others. Other determining factors, such as seriousness of condition and type of disease, were likely to affect the willingness for involvement.

In Category 2, many patients, who had additional social resources in the system, claimed that they liked more information (interview 121, 108 and 422) or shared decision-making (interview 111, 113, 202, 201, 204 and 311). Only a case (interview 313) with an acute condition, who was an elderly man, said he liked exclusion. He trusted his son and their doctor friends in the hospital. It seemed that patients with additional help from professionals did not necessarily lead to an exclusion from decision-making. Nevertheless, it is still not clear about the average group.

Overall, there is some evidence here to reject H10. Although some patients with poor social capital are more likely to want to be involved in their health care, some evidence shows that patients with rich capital also want involvement. Therefore, there emerges some evidence to reject the hypothesis, which could be further tested through other methods, such as quantitative surveys.

6.6 Summary of findings

Similar to patient involvement and participation in western contexts, various patterns of actual involvement in health care decisions emerge: paternalism; professional-determined; shared decision-making; patient-lay carer determined; autonomous decision-making. These patterns provide rich descriptions of how Chinese service users are involved in practice. A special context in China is the central inclusion of family members in health care decisions. Family members are regarded as having an obligation to be involved and given priority in receiving information and treatment decision-making under some circumstances.

In this chapter, I explored motivations for different levels of involvement, including exclusion, information-giving and shared decision-making. Motivations for exclusion include trust in professionals, little confidence in personal health literacy, little experience of health care and psychological burden. Obtaining information is driven by the need for illness management, rights of conditions and learning effects of treatments. Motivations for SDM mainly come from the need to negotiate costs and to express preferences over treatments.

Contexts give meanings to patient involvement and participation and offer explanations of why people want to be involved and why not. I provide a comparative summary of hypotheses and findings below.

In terms of disease-type, the evidence in the first stage of fieldwork shows that patients with chronic conditions are more likely to want to be involved than patients with acute conditions. Evidence in Stage 2 makes it clearer that the chronic condition increases the likelihood of wanting involvement. As users with chronic conditions seem to advocate involvement, policy-makers and practitioners could do more to transfer more power to patients, such as increasing knowledge of illness management, providing quality information and enhancing the confidence for the shared decision-making.

In terms of the stages of cancer patients, the analysis in Stage 1 shows that the later the stages of cancer lead to the increased likelihood of wanting involvement. In Stage 2, some evidence emerges to reject H2, as patients in the middle or late stage of cancer may not want any involvement. This might be due to the seriousness of condition leading to stress and anxiety, which cancer metastasis takes place. It implies that health professionals, managers and policy makers need to respond appropriately to which circumstances cancer patients want what levels of involvement, which is also stressed by Thompson (2007, p. 1308).

The analysis in Stage 1 shows that seriousness of condition might also be a factor. In Stage 2, evidence makes it clearer that with the perception of a not-serious condition, trust in professionals to act appropriately for their benefits reduces the likelihood of wanting involvement. With the perception of a serious condition, the belief of a personal responsibility (to get better) and the perception of a complex condition leading to stress and incomprehension increase the likelihood of wanting involvement. No evidence in Stage 2 makes it clear that with the perception of a non-serious condition, patients who are more confident to talk with professionals are more likely to want involvement. These findings reflect that patients possibly have rich accounts of wanting more or less involvement under different circumstances. It reminds practitioners that perceptions of seriousness are an important context to consider.

The evidence in Stage 1 suggests that younger patients are more likely to want to be involved in their health care. The evidence in Stage 2 makes it clearer about it. It addresses the problem that elderly patients are likely to lack confidence or willingness to be involved in health care delivery. It suggests that family members as lay carers, professionals, managers and policy-makers need to give more voices and power to the elderly patients.

The analysis in Stage 1 shows that concerns over costs increase the likelihood of wanting more involvement. The evidence in Stage 2 makes it clearer on the association between health insurance type and the willingness for involvement. Policy-makers should do more to fill the gaps of RBMI and UEBMI, enabling the equal access to health services among different social groups. Thus, users have better positions to focus on treatments and health outcomes, rather than costs.

In terms of trust, it shows in Stage 1 that distrust in professionals may lead to increasing the likelihood of want involvement. Evidence in Stage 2 makes it clearer on the relationship between trust and the willingness for involvement. It shows that trust is crucial to achieve better communication and health outcomes, but it calls for more policy efforts to rebuilding the relationship between service providers and users.

In the first stage of analysis, evidence shows that rich cultural capital increases the likelihood of wanting information in health care, as it enhances the confidence to engage with professionals. It also shows that poor cultural capital also increases the likelihood of wanting decision-making, despite lacking for the desire for information. It may be possibly due to their concerns over costs and preferences for a cost-effective treatment. More evidence in Stage 2 makes it clearer that cultural capital matters. It requires more attention of policy-makers to fill the gap of health literacy between different groups, which is important to implement user involvement in health care.

In terms of family involvement, it shows that most patients are happy and feel positive about family involvement In Stage 1. It seems that the older and very young patients are more likely to have their family dominate, than the middle-aged and the employed patients. Evidence in Stage 2 makes it clearer about the willingness for more autonomy in the group of middle-aged and working patients, as they feel more confident, competent and control over information and decision-making. It implies that practitioners could possibly enhance the confidence and competency of the elderly and very young patients in medical encounters.

Although it remains unclear about how social capital affect patients' willingness for involvement, further research is needed to explore whether or not social capital increases the likelihood of wanting involvement in health care delivery.

6.7 Concluding remarks

I interviewed service users in four clinical departments in three local hospitals in East China. The empirical fieldwork provides rich accounts of their experience and views of patient involvement and participation. Various patterns of actual and desired involvement are identified, with different levels of patient power in the aspects of information exchange and treatment decision-making. However, involvement may shift depending on the context,

with a range of determining factors influencing the service users' willingness to engage with professionals. Therefore, I abductively explore the contexts that are likely to affect people's attitudes or desire for getting involved in their health care. A range of individual contexts are examined, including disease-type, the stages of cancer, seriousness of condition, age, health insurance type, and doctor-patient relationships. In addition, I also explore the associations between cultural and social contexts and people's desire for involvement.

This chapter mainly focused on patterns and contexts of patient involvement and participation at the micro-level. In the next chapter, I will broaden the discussion to consider how the contexts, economic and social-demographic conditions impact on how users wish to be involved in health care.

Chapter 7 Discussion

7.1 Introduction

The evidence from the previous empirical chapters demonstrates a number of contextual factors that shape how Chinese service users involve themselves and their desire for involvement in their health care. This evidence also offers explanations for why patients and carers get involved or not. In this chapter, I will argue that the Chinese context matters, and it presents a significant influence on how users co-produce health care and whether or not they wish to be involved. The Chinese context is considered in the macro-level, meso-level and micro-level contexts. I will argue that they present obstacles to the opportunities for co-production in health care.

In Section 7.2, I discuss the impact of macro- and meso-level contexts on the willingness of involvement, including marketisation and consumerism, professionalism, the political context and the institutional context. In Section 7.3, I examine how economic and socio-demographic conditions at the micro-level determine the taxonomy of involvement and participation. In Section 7.4, I discuss how and why there exist contrasting views of managers and professionals based on the theory of street-level bureaucracy. In Section 7.5, I examine the barriers to patient involvement and participation in China from the perspectives of various stakeholders and proceed to a further discussion of the theories of co-production.

7.2 Macro- and meso-level contexts

7.2.1 Marketisation and consumerism

While most studies examine patient involvement and participation in other contexts, such as the UK, Canada, Australia and Germany, this study is the first to analyse the impact of marketisation and consumerism on the involvement of Chinese service users and their willingness to be involved in health care delivery. The first impact concerns how health services are funded, which is related to how service users view their positions in health care delivery. Despite the increasing government budgets to promote

accessibility for the Chinese population, a majority of health service users have to share the payment of the escalation of health care expenses. In this regard, a special phenomenon, which has not been indicated by previous studies, is that service users in China are motivated to get themselves involved in health care decisions due to the concerns over costs. They prefer to inquire about the costs of health care interventions from professionals and to balance treatment outcomes against expense. This is reflected particularly from the social groups with a poorer insurance condition, such as rural residents and urban unemployed.

The second impact is the increased demand and rising expectations over services, which is highlighted by Thompson (2020, p. 45) as the main challenge of public service delivery in the current stage. Prior research in other contexts recognise the benefit of choice as the driving force for diversity (Gabriel and Lang, 2006, p. 26). In line with the observation of Hsiao and Hu (2010, p.119) that competition among service providers encourages the investment of new medical technology and enhancement of the prestige of hospitals and specialists, the evidence in Chapter 4 confirms that patients and carers, as consumers, demonstrate a variety of demands and expectations in the market setting, including service quality and treatment outcomes. In a sense, competition and choice stimulate people to have ideas of personalised services and interaction with professionals and providers.

The third impact is related to how health services are delivered. Having gone through marketisation and partly privatisation of health service provision in recent decades, competition is largely promoted by reformers, which echoes similar findings that consumer choices are empowered through competition in health care markets (Fotaki et al., 2008; Gabriel and Lang, 2015; Jung, 2010; Lupton, 1997; 6, 2003). A positive aspect that consumer choice brings about an increased individual competence around information, that more service users as consumers enhance the ability to use a comprehensive source of information for personal choices. Another positive aspect is the increased awareness of rights as consumers, which is also found in other contexts, that service users are given more power of expressing preferences and making rejections (Gabriel and Lang, 2006, p. 26). However,

marketisation and provision also lead to negative impacts on patient involvement and participation; i.e. the decline of trust in health professionals and service providers. This research confirms that distrust in service providers is associated with competition and marketisation in health service delivery, in line with the results of prior studies (He, 2014; Zhang and Sleeboom-Faulkner, 2011). But this study further reveals that the decline of trust is likely to motivate patients and carers to be more involved in health care delivery.

The fourth impact is the diversification of values in health care as a result of the marketised health system. The previous studies provide an understanding of marketisation in health care that service users demonstrate two streams of ideological beliefs: one is the belief in egalitarianism, meaning that health care should be equitable to the general public, which runs against the ongoing neoliberal ideology; the other one is the inegalitarianism, which insists on more individual responsibilities in health care, with more willingness to be involved in health care decisions (Munro and Duckett, 2016, p. 663; Parkinson, 2003, p. 381). The qualitative analysis in this study further supports this. Some evidence in the qualitative analysis shows that elderly and the worse-off are in favour of egalitarianism, while the winners, such as young and the better-off, are supportive of inegalitarianism. Nevertheless, the ongoing marketisation of health care since the 1980s has led to a variety of beliefs in health care that affect how much people wish to exert influence on their own health care.

7.2.2 Professionalism

The interview data in Chapter 5 and 6 indicate a strong belief in professionalism from stakeholders, including local administrators, health board managers, some professionals and patients, although a few interviewed professionals and patients express their willingness for a more balanced relationship. The belief in professionalism mainly demonstrates trust in scientific knowledge and the monopoly over medical knowledge, with the maintenance of altruism and professional autonomy. Local administrators believe that the engagement between professionals and

patients seems to be impossible, as the majority of patients are incapable of being involved in health care decision-making. Some managers also object to it, as they believe patient involvement and participation is of little value in health care delivery. Some interviewed physicians, especially those from the county hospital, are more willing to make suggestions to patients, rather than involve them in health care decisions. A number of patients claim that they are in favour of a paternalist model, whereby professionals make decisions for their patients without involving them. Prior studies in other contexts account for why professionalism is advocated by the society despite the transformation of the healthcare system; i.e. the consumerism approach. For example, Blumenthal (1994, p. 253) reveals that professionalism in the United States is expected by consumers and voters in the health care market, where 'information asymmetry is valued and people want to trust their doctors'. This is also echoed by Jost (2007, p. 112), who argues that '...not all decisions in health care are made by individual consumers or government bureaucrats...Most health care decisions, ..., are made by professionals, primary physicians'. Nevertheless, the results from qualitative analysis in Chapter 5 and 6 are consistent with the prior research in a sense that many stakeholders embrace professionalism and fail to promote patient power. This underlines one of the reasons why patient involvement and participation is not widely promoted in the Chinese health system.

However, the interview data also demonstrates a popular response of resisting consumerism with the advocates of professionalism. This is mainly derived from many professionals and patients, who are opposed to consumerism. Prior research suggests that professionalism is the main barrier to consumerism, as patients are believed to be irrational without any specialised knowledge (Gabriel and Lang, 2006, p. 26; Jost, 2007, p. 99; Lupton, 1997). This study also confirms that some patients are inclined to be dependent and fearful of making decisions. Meanwhile, prior studies illustrate how profit-driven medical practice in the market setting conflicts with altruism as the nature of the medical profession (Hsiao and Hu, 2010; Hui, 2010, p. 379). This analysis supports this when noting that interviewed managers, professionals and patients complain about profit-driven policies. However, more research is required to understand the interaction between professionalism and consumerism.

7.2.3 The political context

Most previous studies discuss patient involvement and participation within democratic political systems, including patient involvement at the clinical level and collective involvement at the organisational and system levels. Some nations have developed an institutional architecture with multilevel designs of involvement among various stakeholders. The political context provides the conditions for engaging patients and the general public in the design and delivery of health services. For example, Thompson (2020, pp. 13–14) illustrates the political factors in Scotland that facilitate the success of patient and public involvement, including ‘the problems of poor health outcomes and austerity of public service delivery since the 1980s, the policy development of patient and public involvement and shared decision-making, and the political change of direction in governing party and related ideology’. But some other developed democracies have encountered challenges in the implementation of patient and public involvement. For example, Haarmann et al. (2010) discuss the challenges of existing collective involvement in health care in the corporatist welfare states, including France, Germany and Netherlands; i.e. the professionalisation of the management under the influence of New Public Management. Nevertheless, the political context in the democratic states shows a political willingness for engaging with civil society organisations and the general public. Each state has a long tradition of autonomous organisations steered by stakeholders (ibid., p.228). There are also political drivers of the legitimacy of democracy that increase citizen power by opening up decision-making processes and developing public participation (Mullen et al., 2011, pp. 23-24) and ineffectiveness of public service delivery; i.e. service users are dissatisfied with the services they receive and lack control over them; policy-makers have to engage with citizens due to the need for optimal distribution of scarce resources (Barnes, 1999, p. 74; Kolasa et al., 2014, p. 159; Rowe and Shepherd, 2002, p. 278).

However, the data in this research shows that China lacks a favourable political context for patient involvement, regardless of individual or collective involvement. Despite pushing individual service users into the economic domain, there exists the main obstacle for collective involvement in the health sector, including the resistance to democratic participation and the restraint on civil society development. This also resonates with other research in the

field of Chinese politics and policy (Duckett, 2008; Huang, 2019, 2013). Meanwhile, the analysis reveals that Chinese service users have little awareness of being involved in the collective approach, although some expect a more responsive state. The absence of political participation and collective involvement in civil society leads to a limited scope for voice in policy-making and service delivery. 'Citizenship' in public services has largely been exercised through consumer choice and exit, which is in line with the research by He and Warren (2011, p. 275).

7.2.4 The institutional context

The analysis in Chapter 5 reveals that some elements of the institutional context are important regarding the impact on people's desire for involvement and participation in health care delivery. Despite more emphasis on quality improvement in recent decades, performance of quality of care seems to make slow progress (Jian et al., 2019; Li and Krumholz, 2019). Hospitals demonstrate various motivations for quality improvement. Tertiary hospitals have stronger motivations for patient involvement as they are more aware of the global research and practice of quality improvement in health care. They value patient satisfaction and develop improvement strategies. The interviews in Hospital 1 and Hospital 2 confirm this, that patient involvement in patient safety is institutionalised, particularly in chronic management, while Hospital 3 remains underdeveloped. But data does not suggest that competition promotes quality improvement. It demonstrates poor perceptions of service satisfaction in tertiary hospitals due to resources being too scarce to meet the demands of service users.

Despite the slow progress in quality improvement as a national strategy, the current institutional design plays a key role in facilitating or constraining patient involvement and participation. Firstly, although the promotion of informed consent ensures the right to full information about treatments, analysis in Chapter 5 demonstrates more expectations from professionals and service users that engagement could be strengthened beyond informed consent. This is because informed consent is scrutinised for shifting responsibilities to patients and their family, under the impression of giving

choices to them. Secondly, the current institutional design gives priority to the involvement of family members, especially for patients with severe conditions. However, qualitative analysis in Chapter 6 reveals some willingness for involving patients at different stages of treatments, rather than family members. Thirdly, the differences in organisational autonomy lead to the variations in practice of promoting patient involvement and participation. As tertiary hospitals have more autonomy in innovating new ideas for quality improvement, practice at the clinical and management levels are greatly encouraged. In contrast, secondary hospitals lack the autonomy of investing in new efforts, which constrains the promotion of patient involvement and participation.

With regard to organisational resources, tertiary hospitals are superior to secondary hospitals in terms of funding from governments, competency to gain profits, human resources and knowledge exchange. A prior study demonstrates that smaller hospitals and those in the rural areas have worse quality of care than large, more esteemed hospitals in China (Jian et al., 2019, p. 969). Although there is limited evidence supporting it in this research, the data in Chapter 5 reveals that involving patients at the clinical level in Hospital 1 and Hospital 2 is more embraced by professionals and managers than in Hospital 3.

The other institutional context is the demography of the population of service users, for which the key feature is the urban-rural distinction. The data analysis in Chapter 5 illustrates that Hospital 1 and Hospital 2 attract many service users who live in the city, while Hospital 3 mainly serves the rural population in the county. Service users from urban areas tend to be more active, while those from rural areas are more likely to be passive and dependent. However, further quantitative research is needed to confirm the association between desire for involvement and the association with urban and rural inhabitants.

7.3 Economic and socio-demographic conditions

The research suggests that the economic conditions measured by health

insurance is a key factor in affecting people's desire for involvement. The results demonstrate that financial concerns do affect how much people want to be involved in health care delivery. Service users in the RBMI scheme are more likely to engage with professionals about the costs of treatment options, while those with UEBMI scheme are less likely to discuss the costs. This is mainly due to the differentiation of out-of-pocket spending in health care among various social groups. Nevertheless, this study is the first to explore the association between health insurance and the desire for involvement in the Chinese context, although some prior studies reveal that financial barriers affect the satisfaction with medical treatments in different contexts (Munro and Duckett, 2016, p. 663; Tam Ashing et al., 2003, p. 53).

The analysis also suggests that socio-demographic conditions are important in influencing how much people desire to be involved in health care delivery, such as age, education background and employment, as previous studies indicate (Rosén et al., 2001; Strull et al., 1984; Sutherland et al., 1989). The interview data shows that the younger, more educated, employed patients are more in favour of obtaining information from various sources, especially from health professionals, although there is no sufficient evidence to support the proposition that this social group is more willing to share decision-making. On the contrary, old, less educated and unemployed patients are less able or willing to involve themselves in health care delivery.

Further, the data reveals that cultural capital has a positive influence on the desire for involvement. As Bourdieu (2011, p. 81) suggests, the distribution of capital structures the positions of individuals and their relationships with others. In the field of health care, as illustrated in the qualitative data, the distribution of cultural capital may possibly determine the positions of patients and their families and affects how much they desire engagement with professionals. Some previous studies reveal that cultural capital contributes to the inequality of treatment (Dubbin et al., 2013, pp. 119-120; Shim, 2010, pp. 9-11). This research confirms that cultural capital is crucial for information-seeking: patients and their families who have rich cultural capital are more inclined to seek information actively, as they are more confident to overcome the gap of health literacy and engage with professionals, whilst

those with poor cultural capital have little knowledge and, therefore, little willingness for information. However, patients with poor cultural capital may be more willing to be involved in decision-making, probably due to their concerns over costs and preferences over a cost-effective treatment. Therefore, cultural capital contributes to the differentiation of competencies in medical interactions, and further affects how much people want to be involved.

The social context also demonstrates the disparities of social connections and resources. The interview data shows that the middle-aged working patients have more willingness to control over health care decisions, compared to retired, elderly patients and young patients who are not working. This may be because middle-aged working patients have more access to social connections and social resources, as they have more opportunities to 'get to know people who are in the positions of authority and have better skills of dealing with them' (Wank, 1999, p. 129). This is consistent with the findings that income and professions are associated with proactive strategies of using social connections or resources to deal with health providers in China (Munro, 2013, p. 160).

7.4 Conflicting values of practitioners: managers and professionals

As demonstrated in Chapter 5, most professionals have a consensus on the benefits of patient involvement and participation in medical practice, although they might involve patients and their families at different levels. On the basis of the interviews, the analysis suggests that professionals greatly value the right of patients to information and their involvement in illness management. Contrastingly, interviewed health board managers demonstrate conflicting opinions over it. Most of them do not value patient involvement and participation at the clinical level, as they believe there is a gap in knowledge and psychological stress. The conflicting opinions over patient involvement and participation indicate that practitioners in the delivery of health services have different understandings and positions on the issue.

In the theory of street-level bureaucracy, Lipsky (1980, pp. 13-17) argues

that street-level bureaucrats play a crucial role in public policy-making, that is, street-level bureaucrats, such as teachers, policemen, prison guards and doctors, make policies through high degrees of discretion in decisions about citizens with whom they interact; they obtain comparative autonomy from organisational authority. With regard to the opinions of promoting patient involvement and participation, the evidence in China echoes the similar observation by Lipsky, that health professionals are more inclined to embrace the involvement of patients and their family in practice, as they are more concerned with quality improvement and better health outcomes. Some of them claim that they have already done it, as they find it effective for illness management, especially in the conditions of chronic disease. Lipsky (1980, p. 17) also explains why there is a distinct degree of noncompliance, as 'lower-level workers' *interests* differ from the interests of those at higher levels'. This is also found in the qualitative analysis, that many health professionals express their unwillingness to implement profit-seeking policies and claim that they do not want to make profits from patients by over-prescription. Even though patient involvement and participation in health care delivery is not a policy, it is given priority by many professionals as it reduces the errors of diagnosis and increases what they believe is an ethical position to adopt.

By contrast, health board managers are more resistant to patient involvement and participation. Lipsky (1980, p. 19) points out that managers are 'properly result-oriented' and are concerned with 'performance and the cost of securing performance'. Most health board managers value informed consent, rather than the engagement between professionals and patients, as they believe it is cost-effective to reduce the rate of medical disputes and increase more consultations and treatments. This also demonstrates the 'conflictual relationship' identified by Lipsky that managers are making efforts to minimise the autonomy of street-level bureaucrats, while street-level bureaucrats attempt to maximise their autonomy (Lipsky, 1980, p. 25). The qualitative analysis of the case of China further supports the argument that some professionals show negative opinions over the regulation of informed consent and expand their communication beyond the necessary forms, as they feel it is not sufficient for sharing responsibilities between patients and themselves. Health professionals, although they are regarded as lower-level

workers, possess additional resources and enhance their power in the organisation, through aspects such as expertise, techniques and personal attractiveness (Lipsky, 1980, p. 25). This confirms that Lipsky's observation that 'the resources of lower-level workers are greater than those often possessed by subordinates in other work contexts.' (ibid.). Nevertheless, there is a shared interest between health professionals and managers, that is, the objective of reducing medical disputes, which enables the compliance with implementing informed consent.

7.5 Barriers to co-production in health care in China

In the previous sections, I illustrated how and why contexts at the macro-level and meso-level impacted on people's desire for involvement in health care delivery. It seems that the system-wide practice of patient involvement and participation in China is seen as a luxury by the citizens, despite the emergence of small-scale practice in some particular clinical departments and health facilities. No specific policy documents or directions regarding the issue are found at state level. Interviewed local administrators and health board managers demonstrate little value and interest in promoting it at the clinical level. Although interviewed professionals, mostly in tertiary hospitals, have a positive attitude towards involving patients, it is not required in medical practice. In this research, I argue that the contexts do matter and in China they present obstacles to the opportunities for co-production in health care. The barriers identified in the Chinese context may not be unique, but they make contributions to the understandings of co-production in theory, which is informed from practice.

Firstly, the ideology of marketisation and consumerism has undermined the mutual trust between two parties. While trust is believed to be the basis for co-production in health care (Thompson, 2007, p. 1308), the organisational objective of generating profits puts professionals in a difficult position of 'seller', rather than acting as partners and co-producers. It is the same with patients and their family members, as they have to bargain with professionals for a cost-effective treatment. This resonates with other non-publicly funded systems where co-production is hindered by distrust between service

providers and users. For example, Ewert and Evers (2014, p. 432) remark that economisation and marketisation in the German health system disturb the equilibrium of the sensitive physician-patient relationship through hidden financial impetus. Nevertheless, not every Chinese service user lacks trust in service providers. According to the analysis in the previous chapters, three groups of service users tend to trust in their professionals: the elderly and the poor have to rely on doctors due to their limited cognitive ability and resources; those who are loyal to certain professionals and health facilities and often with chronic conditions; young and active consumers who are able to use rights of choice and information and exit freely. Apart from these groups, a large number of service users have a relatively distrustful relationship in many circumstances. Therefore, it seems that the success of co-producing health care has to deal with the negative influence of the neoliberal approach of the health system, which is a major barrier in promoting patient involvement and participation in China.

Secondly, the facilitation of various stakeholders with a range of motivations is difficult. As shown in Chapter 6, patients demonstrate a variety of motivations for engagement, including instrumental (cost concerns, preferences over treatment, improving outcomes of health care) and intrinsic benefits (responsible for health). Some also express unwillingness for involvement at some point within certain contexts. For example, patients and their families reveal little control over decision-making in an emergency situation, such as traffic accidents. Some elderly people show little capacity over disease management due to the low level of health cognition. However, the theories of co-production seem to overlook the facilitation of motivations and wants, although some previous studies explore why public sector clients co-produce (Alford, 2002) and why citizens and volunteers co-produce public services (Rosentraub and Sharp, 1981, pp. 529-536). It is well recognised that the nature of health care determines the interdependency of the relationships between patients and professionals, and values the input of patients and their families (Brandsen and Honingh, 2016, p. 433). This study shows that Chinese patients and their families are inclined to embrace co-production, because they have a stake in health and health care. Nonetheless, many of them find it difficult to engage with professionals due to the knowledge gap, psychological stress and other concerns. This may

require service providers to identify different demands and adjust their communication strategies. However, in the case of China, professionals normally have little time and are not trained in the skills to engage with patients, not to mention other stakeholders, such as health board managers and policy-makers, who lack the motivation to promote co-production. Thus, institutional changes are required if professionals are to take the role of facilitating co-production in health care.

Thirdly, co-production in health care is difficult to realise in the developing health system, for example, China. Compared to mature and publicly funded health systems where patient involvement and participation is promoted widely, China is undergoing a rapid development of health technology and facilities, as well as tackling a number of problems including rising costs, low efficiency and inconsistencies in health service provision (Süssmuth-Dyckerhoff and Then, 2017). Due to limited time and resources, there has not been sufficient attention given to the governance structure of involving patients in health care decisions, despite the small-scale practice at the frontline. As China is attempting to promote privatisation and public-private partnerships in the health care industry, it seems that consumer choice is believed to be the main lever to boost efficiency and effectiveness, while the mechanism of voice is overlooked by reformers.

Fourthly, social inequality resulting from the neoliberal approach of marketisation and consumerism provides yet another obstacle to the practice of co-production. The variability of purchasing power, and cognitive and practice abilities, increase the costs and difficulty of involvement activities. In the data analysis, the patients that show the willingness and ability for co-production are those who are young, well-educated and urban users. They have little concern over costs, nor do they distrust doctors. They reveal a willingness for improving health and life quality. In contrast, many cases demonstrating an unwillingness or inability for engagement are mainly the elderly, the less educated and the unemployed. Lay knowledge is also not valued by the majority of service users and providers. Very few respondents are confident in their capability of making contributions to the process of health care delivery. Therefore, co-production in health care needs to

consider the differentiated user influence over health care decision-making. Some evidence in the study also confirms that many respondents only want information, but they feel unable to make decisions with professionals.

7.6 Concluding remarks

In this chapter, I link the practice in China to the theoretical debates of patient involvement and participation. I discuss three important elements of contextualised factors regarding why Chinese patients get themselves involved or not, including the macro- and meso-level contexts, as well as economic and social-demographic conditions. I also look at the conflicting values of health professionals and health board managers, which are relevant to the promotion of patient involvement and participation. Lastly, I argue that the Chinese context is a crucial factor in obstructing the opportunities for co-production in health care, including the ideology of marketisation and consumerism, ineffective facilitation of collective work, the underdeveloped health system and the issue of social inequality. Overall, Chapter 7 enables a better understanding of the Chinese context, through the interplay of various contextual factors, that give meaning to patient involvement and participation in theory.

Chapter 8 Conclusion

The study seeks to answer a fundamental question: What does patient involvement and participation mean in Chinese hospitals? Three sub-questions are proposed and analysed regarding the meaning of patient involvement and participation: To what extent are patients involved and wish to be involved in their health care? Within which contexts do patients wish to be involved? How do these macro- and meso-level contexts, as well as economic and socio-demographic conditions impact on how users wish to be involved in their health care? To answer these questions, I use the case study method with qualitative methods to understand the issue in China. As the context of patient involvement and participation is new and unknown, I use ARS that draws on interviews at the first stage of fieldwork to generate the emergent hypotheses and test it deductively at the second stage of fieldwork. I also involve other stakeholders (i.e. professionals, health board managers, an NGO leader, academics and local administrators) to understand their views of patient involvement and participation after the analysis of policy documents at the state level. This enables a comprehensive exploration of the issue through the lens of various stakeholders. The findings are summarised in the following sections below.

8.1 Summary of findings

8.1.1 The macro-level and meso-level contexts

My research is based on the analysis of contexts at the macro- and meso-level. I demonstrate that political, policy and institutional contexts play a crucial role in affecting the willingness for getting involved in health care decisions. Firstly, the impact of marketisation and consumerism in recent decades in China leads to an increased willingness for engagement between professionals and patients due to the concerns over costs and an increased expectation of services. People are eager to know treatment outcomes from professionals. It also boosts diversity of demand for services, such that people have had more choices than ever before. More people tend to seek personalised services that they can afford. The marketisation in health care motivates Chinese consumers to be knowledgeable and active given the various choices and information. The impacts of marketisation include a

decline of trust in professionals and varied beliefs in markets; e.g. egalitarianism and inegalitarianism. The decline of trust leads to more willingness for involvement due to concerns over decisions being made on their behalf. People with the belief of inegalitarianism, who believe in individual responsibility for health care, embrace more involvement and responsibility in health care delivery. People with the belief of egalitarianism, believing in equitable rights of health care, tend to reject more personal involvement in their health care.

Secondly, professionalism is a determining factor in hindering the promotion of patient involvement and participation. In the Chinese context, professionals often have superior knowledge and occupy a dominant position in the medical encounter. The evidence shows that many stakeholders, including local administrators, some health board managers, physicians in the hospitals and some patients, embrace professionalism. They show resistance to patient power and believe that patient involvement and participation is not greatly valued. Nevertheless, consumerism is placed in opposition to professionalism, which eliminates the benefit of altruism in professionalism and results in a distrustful relationship between professionals and patients.

Thirdly, unlike developed democracies, China lacks a favourable political context for patient and public involvement in the health sector. The absence of political participation and civil society engagement in China makes it difficult to engage with users and the general public at various levels of service design and delivery. Citizenship in the delivery of health services is exercised through consumer choice and exit.

Fourthly, there is limited policy support for patient involvement and participation in China, although current policies and legislation reinforce the right to information in health care delivery. Patient involvement and participation are not given priority in health reforms in China and health policy-making is largely dominated by the central government, which does not value the involvement of service users in the process of decision-making.

Lastly, the institutional context is a key factor in affecting how much people wish to be involved in health care delivery. In the market setting, tertiary hospitals in China have more motivation to involve patients at the clinical level than secondary hospitals, as they are more aware that user involvement contributes to quality improvement in health care delivery. The current design of informed consent, with the emphasis on family involvement in decision-making and differences in organisational autonomy and resources, hinder the implementation of patient involvement and participation. Moreover, desire for involvement is affected by the demography of the population of service users, for which the key feature is the urban-rural distinction. The evidence in the qualitative analysis suggests that service users from the urban area tend to be more active, while those from rural areas are more passive and dependent.

8.1.2 The micro-level context

An abductive approach is used to generate a series of emergent hypotheses for potential factors at the individual level associated with the desire for involvement. These factors include the type of disease, stages of cancer, seriousness of illness, age, health insurance type, doctor-patient relationship, cultural capital and the social context. Subsequently, I test the hypotheses in the second stage of fieldwork. I have examined the variations of individual contexts in health care delivery, which allow me to ascertain that the willingness for involvement and participation is affected by a range of factors.

The first determining factor is health insurance. The qualitative results demonstrate that financial concerns are likely to affect how much patients desire involvement and participation. Service users within the RBMI scheme are more willing to engage with professionals due to the concern of costs, while UEBMI users have fewer motivations for involvement in decision-making due to costs being a lesser concern for them.

The socio-demographic conditions, including age, education and

employment, are playing a key role in affecting the willingness for involvement and participation. The results indicate that younger, more educated and employed patients have more willingness to obtain information from various sources, especially from health professionals. Those who are older, less educated and unemployed patients are not well-prepared to seek information and sometimes making shared decisions.

Cultural capital is also a significant factor influencing people's desire for involvement and participation. Cultural capital contributes to the differentiation of competencies in medical interactions, and further affects how much people want to be involved. Patients with rich cultural capital are more likely to seek information actively from professionals. Patients with poor cultural capital are less likely to obtain information actively. But patients with poor cultural capital are more likely to want involvement in decision-making, as they are more likely to negotiate and find a balance between treatment outcomes and costs.

The social context also demonstrates the disparities of social networks and social resources. It indicates that the middle-aged and working patients have more willingness to control over health care, compared to retired, elderly patients and young patients who are not working. It is not clear about social capital. More evidence is needed to further test the relationship with patients' willingness for involvement.

Type of disease and seriousness of condition are two determining factors. Patients with chronic conditions tend to want more involvement in their health care, while patients with acute conditions are less likely to want involvement. Seriousness of illness is likely to affect how much people want involvement. For instance, trust in professionals to act appropriately, and perception of complexity due to stress and incomprehension may all associate with less willingness for involvement. More sense of personal responsibility to get better leads to more likelihood of wanting involvement. However, the seriousness of illness might be interrelated with other factors, such as age, disease-type, cultural capital and insurance type. The stages of cancer might be correlated with patients' willingness for involvement, but there is yet no

clear and direct relationship. Overall, these are tentative findings and more empirical studies are needed to support these findings.

8.1.3 Patient involvement and participation in China

A special context in China is the priority of involving family members in information exchange and the decision-making process. This is particularly the case when the condition of illness is serious, or the patient is elderly. It is believed that the most vulnerable patients should be excluded from decision-making due to the concern of psychological stress that it places on them.

Drawing upon the taxonomy of a previous study (Thompson, 2007, pp. 1302-1307), five typological categories of patient involvement and participation are identified in the fieldwork: paternalism, professional-determined, shared decision-making, patient-lay carer determined, autonomous decision-making. To what extent do patients wish to be involved in health care delivery? Three levels of involvement and participation are identified in the interviews: exclusion, receiving information, sharing decision-making. No respondent prefers the patient-lay carer determined model, with information being actively sought by patients and their families and decisions being made mainly by them. Respondents also show no willingness for the autonomous decision-making model, with patients not necessarily needing any information from health professionals and not giving the power of decision-making to anyone else. Although the latter models of patient involvement and participation do not exist empirically, it exists in theory (see Thompson, 2007: p. 1307). The patient-lay carer determined model and the autonomous decision-making model mean that patients have the power to control their own decision-making without relying on professionals. It indicates that no respondents in the sample reveal any confidence or willingness for self-determination of health care in practice. However, there may be situations where such a *modus operandi* is preferred, such as patients who has been self-managing their care for a considerable period of time, with minimal input from health professionals.

8.1.4 Conflicting values between health managers and professionals

The evidence from the qualitative analysis shows that most health professionals greatly value the involvement of patients in health care delivery. Yet, some interviewed health board managers demonstrate conflicting opinions over it. The theory of street-level bureaucracy suggests that those lower-level workers have different interests from those at higher levels. Many health professionals value patient involvement and participation due to the benefits of improving service quality and achieving improved health outcomes. However, health board managers are more resistant to it due to their concerns over performance and costs. The 'conflictual relationship' between health board managers and professionals leads to different positions in health care delivery. Health professionals tend to expand their autonomy in medical practice, while managers tend to minimise their autonomy. In this regard, professionals in some clinical departments embrace the promotion of patient involvement and participation, although managers are not actively engaged with it. However, the relationship implies some shared interest, which explains why informed consent is well implemented.

8.1.5 The implication for co-production in health care in China

The Chinese context presents obstacles to the opportunities for co-production in health care. The ideology of marketisation and consumerism has undermined the mutual trust between health service providers and users, which becomes a main obstacle for co-production in health care. While lack of trust becomes a major social issue in China, many service users tend to bargain with professionals for a cost-effective treatment. They also show higher expectations over treatment outcomes, as they regard themselves as consumers who pay for effective health care. Professionals feel unhappy about their role as 'sellers', which is in conflict with the nature of altruism. Secondly, there is no effective facilitation of collective work in health care delivery. Despite the desire for co-producing health care for service users, health professionals have little time and training for facilitating these activities. Thirdly, the current Chinese health reform does not give priority to the inclusion of voice of patients and carers. In the institutional design of the health system, consumer choice is believed to enhance efficiency and

effectiveness, rather than the mechanism of voice. Fourthly, the social inequality, a result of the neoliberal approach of marketisation and consumerism, provides another obstacle to the practice of co-production. The young, well-educated and urban users are more confident to engage with professionals due to their high level of cognitive abilities and purchasing power. The elderly, the less educated and the unemployed users feel difficult and lack confidence in sharing decision-making with professionals.

8.2 Reflection

8.2.1 Generalisability

I use the case study method to explore in depth the factors associated with people's desire for involvement and to make theoretical generalisations. This study does not intend to make representational generalisations or inferential generalisations (Ritchie et al., 2014, pp. 348-352). Firstly, this research has not been designed to make representative generalisations, that is generalising to the population from which the sample is drawn. I use a convenience sampling approach to identify the available sample at the first stage and a purposive sampling approach to select sample units with particular features at the second stage. Convenience sampling is criticised for its lack of diversity (ibid., pp. 115-116) and purposive sampling does not have sufficient representation of the population. These sampling approaches do not seek to achieve the diversity and representative of the parent population.

Secondly, the selection of the study area inhibits inferential generalisation that is generalising to other settings and contexts. The inferential generalisation requires 'researchers to anticipate, and to understand in depth, the full range of other populations or settings which might hold appropriate resemblance, or for which the transfer of findings might have relevance' (Ritchie et al., 2014, p. 352). There are many context-specific characteristics in other contexts (i.e. other provinces) or other settings (e.g. primary care services; mental health services), such as organisational and institutional features, the demography of the population, and political and policy contexts. The three-case design of patient involvement and participation in Shandong

Province in China does not seek to generalise the findings from one context to another.

However, there are some existing surveys relevant to Chinese health care nationally, which are possibly relevant to the findings of the study. One of the outputs of the China National Health Attitudes Survey suggests that the unethical medical practices, which partly derived from marketisation in China, seriously reduce the perception of user satisfaction and service quality (Munro and Duckett, 2016, p. 662). The National Health Services Survey, conducted by NHFPC, released the outcomes of the performance evaluation in 2013. The reasons for the dissatisfaction of outpatients and inpatients include high costs (40.0%, 40.2%), poor medical skills (16.1%, 16.1%) and poor service attitudes (13.8%, 14.8%) (NHFPC, 2013, pp. 56-59). Compared to the national survey in 2008, reasons including the lack of medical equipment and medicine, poor medical environment and the complex procedure of inpatient services have no longer been the major problems (NHFPC, 2013, pp. 56-59; MOH, 2008, p. 26). These outputs are in line with some of the findings in the study, suggesting marketisation is one of the contributory contexts for a lack of patient and public involvement in health care.

As Blaikie (2010, pp. 216-217) suggests, the approach for generalising study findings is established through the increase of heterogeneity of the population in the selected cases. First, I ensure the heterogeneity of selected cases to increase the generalisability of the research. I select three different types of hospitals: a teaching hospital at the city level, a non-teaching hospital at the city level and a non-teaching hospital at the county level. This is because different types of health facilities attract different service users. City hospitals are more likely to attract urban and rural service users in the city and other neighbour cities, while county hospitals mainly attract urban and rural service users within the county. Second, I increase the heterogeneity of the population by selecting the sample of cases with a range of diversity, including socioeconomic characteristics (i.e. age, health insurance type) and type of disease.

Ritchie and Lewis (2014, pp. 354-359) propose two criteria for generalisation in qualitative research: reliability and validity. Reliability refers to the degree to which research findings could be repeated with the same or similar methods (ibid.). To ensure reliability, I conduct pilot interviews and hold a review meeting with medical staff. The wording of interview questions is reviewed and readjusted prior to the interviewing process. Dialect is used to interview local service users, as it enhances the quality of interpretation. The relationship between participants and interviewer is not hierarchical, as I show my identity as a PhD student to gain the support from potential participants. Each interview is conducted independently to prevent the influence of other social actors.

Validity refers to the 'correctness' or 'precision' of research findings (Ritchie and Lewis.,2014, p. 356). It is achieved by meeting the criteria of credibility and consistency. In terms of credibility, some approaches to validating qualitative data are used in the process of data analysis. First, I use a widely applied and accepted technique for data analysis to increase the credibility of the findings; i.e. the framework approach and thematic analysis for qualitative data analysis. It enables me to explore and interpret data case by case and map the dynamics of patient involvement and participation at the clinical level. Based on the preliminary coding of the first few transcripts, I develop a working analytical framework for data management and analysis. It is managed through Nvivo 11.0, which is recognised as high-quality software for qualitative analysis. Second, I adopt the technique of triangulation to add to the credibility of the findings (Maxwell, 2009, p. 245). I use triangulation of sources by collecting various sources of data to draw conclusions, including primary data (i.e. interviews) and secondary data (i.e. policy documents). I also apply triangulation through multiple analysis by interviewing various stakeholders and comparing their views of involvement and participation in the process of data collection and interpretation. I adopt theory triangulation by looking at data from different theoretical perspectives, including the theories of co-production, governance, citizenship and capital. This strengthens the confidence of drawing conclusions with regard to patient involvement and participation in the Chinese context. I do not adopt the approach of member checking to confirm whether or not the meaning or interpretation of data is correct by those who contribute to the research. This

is mainly because very few respondents are willing to give their contact details at the end of the interview. It becomes extremely difficult for me to verify the validity of evidence through this approach.

In terms of consistency, I argue that there is a basis for extending the theoretical statements from one province to other provinces in China. Firstly, I increase the heterogeneity of cases by selecting hospitals at the city and county levels, as well as sample units with various socioeconomic characteristics and medical conditions. This approach ensures a robust generalisation from a limited number of cases. Secondly, the policy documents relevant to patient involvement and participation are collected at the state level, rather than the local level. This allows for stronger judgements about the generalisability, as there is 'the similarity of dynamics' and 'the universality of the phenomenon' regarding patient involvement and participation in other parts of the country (see Hammersley, 1992, pp. 86-93). Thirdly, the results from the study corroborate the findings from other research that demonstrate the contexts of patient involvement and participation play a key role in determining the desire of service users for involvement in their health care.

Nevertheless, there are factors that affect the generalisation of the research findings. First, the small sample size with 155 respondents (95 at the first stage and 60 at the second stage) reduces the explanatory power of the results. Large-scale sampling is not possible due to limited time and resources. Second, the case study design only involves city and county hospitals. No cases of provincial hospitals and primary health centres are included in the case study design. There is no personal access to provincial hospitals due to limited social networks, which are crucial to gain access (Solinger, 2006, pp. 157-158). Involvement in primary health care settings are not given a focus in this study, as most of the primary care centres mainly provide basic clinical care and public health services in China (Wang et al., 2011, p. 38). Third, only four types of disease are selected in the research design, including coronary heart disease, breast cancer, acute intestinal tract disease and accidental injury. The study does not include other medical conditions due to limited time and resources. Overall, these limitations may

reduce the possibility to generalise the research findings.

8.2.2 Methods

This is qualitative research, consisting of semi-structural interviews in two stages, and analysis of policy documents. Arguably, qualitative methods are ideal when researchers want to understand an issue in a new context. This research absorbs rich and valuable accounts of experience, views and attitudes from respondents, rather than a series of numerical measurements in a quantitative form. These meanings and descriptions provide a robust basis for exploring the research question and generating hypotheses. As Blaikie (2010, p. 213) suggests, 'it is only after work has been done on it, to transpose words into numbers, that quantitative data come into being.' Through ARS, I generate emergent hypotheses regarding the individual context of patient involvement and participation. I then use qualitative methods in the second stage of data collection. This is seen as preferential to conduct a sequential quantitative method for testing the emergent hypotheses deductively, as time and resources are too limited to conduct a survey.

One of the flaws of qualitative interviewing is the complexity and lack of control regarding data collection and analysis. For example, I am struggling to categorise respondents with various levels of CC and SC; i.e. high level, low level and average level. I find it difficult to map the patterns of willingness within the average group and there is some overlap between the average group and the high/low groups. A two-way split might be useful if I categorise respondents with two groups (i.e. high/low level), but a quantitative method may provide a better instrument for measuring the features of cases with different levels of CC and SC. Therefore, qualitative methods are not the only methods that could be adopted in the second stage of data collection. A quantitative survey is valuable to measure important concepts, such as the taxonomy of involvement, cultural capital and social capital. It is also of significance to find the associations between the individual context and desire for involvement due to the robustness of establishing correlations.

8.3 Main contributions

The qualitative research provides preliminary insights into understanding the views and values of patient involvement and participation from various stakeholders in the health care setting in China. It particularly looks at the willingness for involvement in health care through the eyes of service users. As no study has comprehensively examined the individual context of patient involvement and participation in China, the thesis contributes to understanding how socio-economic status and socio-demographic conditions affect the willingness of users for involvement in health care delivery. The thesis elaborates on the contexts at the micro-level with the individual, cultural and social contexts.

In parallel, the research analyses wider political, policy and institutional contexts. It offers important implications of why patient involvement and participation are not widely promoted in China. The political context has a macro-level explanation of why user involvement at the collective level is not popular. It addresses the ideological impacts of marketisation and consumerism on the relationships among stakeholders. It also asserts that the most vulnerable groups lack the mechanism of voice due to their limited resources and capacity for making choices.

Further, the analysis of the policy and institutional contexts allows a good understanding of how various factors promote and/or hinder patient involvement and participation, including the lack of policy support, institutional design, organisational autonomy and resources, as well as the demography of the population. These contexts enable an in-depth analysis of the practice of co-production in health care. It therefore contributes to the understanding of the barriers to co-production in health care in China.

8.4 Recommendations for further research

The qualitative approach only allows the preliminary analysis of variables of patient involvement and participation. Although it is the basis to understand the issue systematically, further quantitative methods are needed to

elaborate on the associations between contexts and the willingness for involvement. As there are no specific surveys relevant to patient and public involvement in China, I suggest the first step is the implementation of a quantitative survey. Quantitative surveys are needed to develop predictive models of which patients prefer which levels of involvement and participation, with a large-scale sample across the country.

Moreover, I collect empirical evidence to support the argument that the marketisation and consumerism of the Chinese health system are the major reasons for the underdevelopment of patient involvement and participation. I suggest that more research in China should focus on the underlining problems and the consequences on quality improvement. I also suggest that research on the comparisons of patient involvement and participation among different health systems (e.g. publicly-funded and market-based health systems) is required.

The exploration of the Chinese context has highlighted the policy problems of insufficient attention to patient involvement and participation. My study suggests that more policy interventions and efforts are needed to overcome the obstacles to co-production in health care, such as improving the health literacy of patient groups, providing quality information about treatments, involving patients and families in shared decision-making, and enhancing the communicative skills of health professionals in consultations and treatments.

The analysis has also highlighted the differentiation of the institutional context. I suggest more research and policy interventions being conducted in county hospitals. As indicated in the study, the problems in the county hospitals include the lack of institutional design with user involvement and organisational autonomy with the introduction of human resources and opportunities for knowledge exchange, and the insufficient resources on patient involvement and participation. More studies are required to examine the barriers to co-production at the county level.

Methodologically, research using ARS is relatively undeveloped in social

science, generally, despite its value in enabling a progressive approach to the development of testable hypotheses. Although the thesis applies ARS to address the policy problem of patient involvement and participation in China, it only makes the case for how ARS could be applicable to this field. I suggest more empirical studies looking at the application of ARS in political science and public policy, as part of a mixed methods research strategy.

References

- 6, P., (2003). 'Giving Consumers of British Public Services More Choice: What can be Learned from Recent History?' *Journal of Social Policy* 32, 239. <https://doi.org/10.1017/S0047279402006980>
- Abel, T., (2008). 'Cultural capital and social inequality in health', *Journal of Epidemiology & Community Health* 62, e13–e13. <https://doi.org/10.1136/jech.2007.066159>
- Agner, J., Braun, K.L., (2018). 'Patient empowerment: A critique of individualism and systematic review of patient perspectives'. *Patient Education and Counseling* 101, 2054–2064. <https://doi.org/10.1016/j.pec.2018.07.026>
- Alford, J., (2002). 'Why do public-sector clients coproduce? Toward a contingency theory'. *Administration & Society* 34, 32–56.
- Alford, J., (2014). 'The Multiple Facets of Co-Production: Building on the work of Elinor Ostrom'. *Public Management Review* 16, 299–316. <https://doi.org/10.1080/14719037.2013.806578>
- Angel, S., Frederiksen, K.N., (2015). 'Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies'. *International Journal of Nursing Studies* 52, 1525–1538. <https://doi.org/10.1016/j.ijnurstu.2015.04.008>
- Annas, G. & Healey, J., (1974). 'The Patient rights advocate: redefining the doctor-patient relationship in the hospital context'. *Vanderbilt Law Review*, 27(2), pp.243-269.
- Armstrong, N., Herbert, G., Aveling, E.-L., Dixon-Woods, M., Martin, G., (2013). 'Optimizing patient involvement in quality improvement'. *Health Expect* 16, e36–e47. <https://doi.org/10.1111/hex.12039>
- Barnes, M., (1999). 'Users as citizens: collective action and the local governance of welfare'. *Social Policy & Administration* 33, 73–90.
- Barnes, M., Newman, J., Knops, A., Sullivan, H., (2003). 'Constituting "the public" in public participation'. *Public Administration* 81, 379–399. <https://doi.org/10.1111/1467-9299.00352>
- Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L., Hartung, H., (2016). 'Coproduction of healthcare service'. *BMJ Quality & Safety* 25, 509–517. <https://doi.org/10.1136/bmjqs-2015-004315>
- Benbassat, J., Pilpel, D., Tidhar, M., (1998). 'Patients' Preferences for Participation in Clinical Decision Making: A Review of Published Surveys'. *Behavioral Medicine* 24, 81–88. <https://doi.org/10.1080/08964289809596384>
- Beusekom, I., Tönshoff, S., de Vries, H., Spreng, C., Keeler, E.B., (2004). *Possibility or utopia? Consumer choice in health care: A literature review*. Santa Monica: RAND Corporation. Available at https://www.rand.org/pubs/technical_reports/TR105.html (Accessed: 19 June 2020)
- Bevir, M. (2013). *A Theory of Governance*. Retrieved from <https://escholarship.org/uc/item/2qs2w3rb>
- Bian, L. (2015). Medical individualism or medical familism? A critical analysis of China's new guidelines for informed consent: the basic norms of the documentation of the medical record. *Journal of Medicine and Philosophy*, 40(4), 371-386. <https://doi.org.ezproxy.is.ed.ac.uk/10.1093/jmp/jhv016>

- Blaikie, N., (2010). *Designing social research 2nd Edition*. Cambridge: Polity Press.
- Blaikie, N. & Priest, J., (2017), *Social Research: Paradigms in Action*, Polity Press, Chicester. Available from: ProQuest Ebook Central. [9 December 2020].
- Blanchard, C.G., Labrecque, M.S., Ruckdeschel, J.C., Blanchard, E.B., (1988). 'Information and decision-making preferences of hospitalized adult cancer patients'. *Social science & medicine* 27, 1139–1145.
- Bloom, G., G., X.Y., (1997). 'Health sector reform: Lessons from China'. *Social Science & Medicine* 45, 351–360. [https://doi.org/10.1016/S0277-9536\(96\)00350-4](https://doi.org/10.1016/S0277-9536(96)00350-4)
- Blumenthal, D., (1994). 'The vital role of professionalism in health care reform'. *Health Affairs* 13, 252–256. <https://doi.org/10.1377/hlthaff.13.1.252>
- Blumenthal, D., Hsiao, W., (2005). 'Privatization and Its Discontents — The Evolving Chinese Health Care System'. *New England Journal of Medicine* 353, 1165–1170. <https://doi.org/10.1056/NEJMp051133>
- Bourdieu, P., (2011). 'The forms of capital (1986)'. in: Szeman, I. & Kaposy, T. (ed.) *Cultural theory: An anthology*. Chichester; Malden, Mass.: Wiley-Blackwell, pp.81–93.
- Bovaird, T., (2007). 'Beyond Engagement and Participation: User and Community Coproduction of Public Services'. *Public Administration Review* 67, 846–860. <https://doi.org/10.1111/j.1540-6210.2007.00773.x>
- Brandsen, T., Honingh, M., (2016). 'Distinguishing Different Types of Coproduction: A Conceptual Analysis Based on the Classical Definitions'. *Public Admin Rev* 76, 427–435. <https://doi.org/10.1111/puar.12465>
- Brett, J., Staniszezwska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., Suleman, R., (2014). 'Mapping the impact of patient and public involvement on health and social care research: a systematic review'. *Health Expectations* 17, 637–650. <https://doi.org/10.1111/j.1369-7625.2012.00795.x>
- Brudney, J.L., England, R.E., (1983). 'Toward a Definition of the Coproduction Concept'. *Public Administration Review* 43, 59. <https://doi.org/10.2307/975300>
- Bryman, A., (2012). *Social research methods, Fourth edition*. Oxford, England: Oxford University Press.
- Buetow, S., (1998). 'The scope for the involvement of patients in their consultations with health professionals: rights, responsibilities and preferences of patients'. *Journal of medical ethics* 24, 243–247.
- Burke, N.J., Joseph, G., Pasick, R.J., Barker, J.C., (2009). 'Theorizing Social Context: Rethinking Behavioral Theory'. *Health Educ Behav* 36, 55S–70S. <https://doi.org/10.1177/1090198109335338>
- Burns, L.R., Huang, Y., (2017). 'History of China's Healthcare System', in: Burns, L.R., Liu, G.G. (ed.), *China's Healthcare System and Reform*. Cambridge: Cambridge University Press, pp. 31–74. <https://doi.org/10.1017/9781316691113.004>
- Butler, C., Greenhalgh, T., (2011). 'What is already known about involving users in service transformation', in: Greenhalgh, T., Humphrey, C., and Woodard, F. (ed.), *User Involvement in Health Care*. Wiley-Blackwell, pp. 10–27.
- Cairney, P., (2011). *Understanding public policy: Theories and issues*. Palgrave Macmillan.
- Callaghan, Gillian.D., Wistow, G., (2006). 'Publics, Patients, Citizens,

- Consumers? Power and Decision Making in Primary Health Care'. *Public Administration* 84, 583–601. <https://doi.org/10.1111/j.1467-9299.2006.00603.x>
- Cartwright, J., Crowe, S., Heneghan, C., Perera, R., Badenoch, D., (2011). *Patient and public involvement toolkit*. Chichester, West Sussex, UK; Hoboken, NJ BMJ: Books/Wiley-Blackwell.
- Cayton, H., (2004). *Better information, better choices, better health: Putting information at the centre of health*. Quarry Hills, UK: Department of Health 37.
- Charles, C., DeMaio, S., (1993). 'Lay Participation in Health Care Decision Making: A Conceptual Framework'. *Journal of Health Politics, Policy and Law* 18, 881–904. <https://doi.org/10.1215/03616878-18-4-881>
- Charles, C., Gafni, A., Whelan, T., (1997). 'Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango)'. *Social Science & Medicine* 44, 681–692. [https://doi.org/10.1016/S0277-9536\(96\)00221-3](https://doi.org/10.1016/S0277-9536(96)00221-3)
- Chen, L., Ryan, J. & Saich, T. (2014). 'Introduction'. in: J. Ryan, L. C. Chen, & T. Saich (ed.) *Philanthropy for health in China*. Bloomington: Indiana University Press, pp. 1-15.
- Cherry, M.J., & Fan, R., (2015). 'Informed consent: the decisional standing of families'. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 40(4), 363-370 <https://doi.org/10.1093/jmp/jhv012>
- Clayman, M.L., Gulbrandsen, P., Morris, M.A., (2017). 'A patient in the clinic; a person in the world. Why shared decision-making needs to center on the person rather than the medical encounter'. *Patient Education and Counseling* 100, 600–604. <https://doi.org/10.1016/j.pec.2016.10.016>
- Cornwall, A., Shankland, A., (2008). 'Engaging citizens: Lessons from building Brazil's national health system'. *Social Science & Medicine* 66, 2173–2184. <https://doi.org/10.1016/j.socscimed.2008.01.038>
- Cotton, M., (2014). *Ethics and technology assessment: a participatory approach*, Springer.
- Coulter, A., (2003). 'Patient information and shared decision-making in cancer care'. *Br J Cancer* 89, S15–S16. <https://doi.org/10.1038/sj.bjc.6601080>
- Coulter, A., (2005). 'Shared decision-making: the debate continues'. *Health Expectations* 8, 95–96. <https://doi.org/10.1111/j.1369-7625.2005.00330.x>
- Coulter, A., (2011). *Engaging patients in healthcare*. Maidenhead: Open University Press.
- Coulter, A., Ellins, J., (2007). 'Effectiveness of strategies for informing, educating, and involving patients'. *BMJ* 335, 24–27. <https://doi.org/10.1136/bmj.39246.581169.80>
- Coulter, A., Entwistle, V., Gilbert, D., (1999). 'Sharing decisions with patients: is the information good enough?' *BMJ* 318, 318–322.
- Coulter, A., Fitzpatrick, R., (2000). 'The Patient's Perspective regarding Appropriate Health Care' in: Albrecht, Gary L, Fitzpatrick, Ray & Scrimshaw, Susan C (ed.), *Handbook of Social Studies in Health and Medicine*, London: SAGE Publications Ltd., pp. 454-464. <https://doi.org/10.4135/9781848608412>
- Cribb, A., Donetto, S., Entwistle, V., (2011). 'Patient involvement: from guidelines to good practice'. *Prescriber* 22, 30–36. <https://doi.org/10.1002/psb.770>

- Curtis, M., (1979). *Totalitarianism*. Transaction Publishers.
- Dittmer, L., (1995). 'Chinese Informal Politics'. *The China Journal* 34, 1–34.
<https://doi.org/10.2307/2950131>
- Dowding, K. (2016). 'Albert O. Hirschman, *Exit, Voice and Loyalty: Responses to Decline in Firms, Organizations, and States*', In: Balla, Steven J., Lodge, Martin, & Page, Edward. (ed.) *The Oxford Handbook of Classics in Public Policy and Administration*, Oxford: Oxford University Press, pp. 256–267.
Doi:10.1093/oxfordhpb/9780199646135.013.30
- Driever, E.M., Stiggelbout, A.M., Brand, P.L.P., (2019). 'Shared-decision making: Physicians' preferred role, usual role and their perception of its key components'. *Patient Education and Counseling* S0738399119303209. <https://doi.org/10.1016/j.pec.2019.08.004>
- Dubbin, L.A., Chang, J.S., Shim, J.K., (2013). 'Cultural health capital and the interactional dynamics of patient-centered care'. *Social Science & Medicine* 93, 113–120.
<https://doi.org/10.1016/j.socscimed.2013.06.014>
- Duckett, J., (2008). 'Health NGOs: a second generation of policy advocates?' *China Review*, 42 (6). p. 16 ISSN 1359-5091.<http://eprints.gla.ac.uk/47466>.
- Duckett, J., (2011). *The Chinese State's Retreat from Health: Policy and the Politics of Retrenchment*. Routledge.
- Duckett, J., Langer, A.I., (2013). 'Populism versus Neoliberalism: Diversity and Ideology in the Chinese Media's Narratives of Health Care Reform'. *Modern China* 39, 653–680.
<https://doi.org/10.1177/0097700413492602>
- Duckett, Jane et al., (2016). Does distrust in providers affect health-care utilization in China? *Health policy and planning*, 31(8), pp.1001–1009.
<https://doi.org/10.1093/heapol/czw024>
- Dummer, Trevor J.B & Cook, Ian G, (2007). Exploring China's rural health crisis: Processes and policy implications. *Health policy (Amsterdam)*, 83(1), pp.1–16. doi: 10.1016/j.healthpol.2006.12.002
- Dunston, R., Lee, A., Boud, D., Brodie, P., Chiarella, M., (2009). 'Co-Production and Health System Reform - From Re-Imagining To Re-Making'. *Australian Journal of Public Administration* 68, 39–52.
<https://doi.org/10.1111/j.1467-8500.2008.00608.x>
- Durose, C., Richardson, L., (2016). *Designing Public Policy For Co-Production: Theory, practice and change*. Bristol, UK: Policy Press.
- Emanuel, E.J., Emanuel, L.L., (1997). 'Preserving community in health care. Journal of Health Politics', *Policy and Law* 22, 147–184.
- Entwistle, V.A., Brown, R.C.H., Morgan, H.M., Skea, Z.C., (2014). 'Involving Patients in Their Care'. *Curr Breast Cancer Rep* 6, 211–218.
<https://doi.org/10.1007/s12609-014-0151-2>
- Entwistle, V.A., Cribb, A., Owens, J., (2018). 'Why Health and Social Care Support for People with Long-Term Conditions Should be Oriented Towards Enabling Them to Live Well'. *Health Care Analysis* 26: 48–65. <https://doi.org/10.1007/s10728-016-0335-1>
- Entwistle, V.A., France, E.F., Wyke, S., Jepson, R., Hunt, K., Ziebland, S., Thompson, A., (2011). 'How information about other people's personal experiences can help with healthcare decision-making: A qualitative study'. *Patient Education and Counseling* 85, e291–e298.
<https://doi.org/10.1016/j.pec.2011.05.014>
- Entwistle, V., Prior, M., Skea, Z.C., Francis, J.J., (2008). 'Involvement in treatment decision-making: Its meaning to people with diabetes and implications for conceptualisation'. *Social Science & Medicine* 66,

- 362–375. <https://doi.org/10.1016/j.socscimed.2007.09.001>
- Entwistle, V.A., Watt, I.S., (2006). 'Patient involvement in treatment decision-making: The case for a broader conceptual framework'. *Patient Education and Counseling* 63, 268–278. <https://doi.org/10.1016/j.pec.2006.05.002>
- Eriksson, E.M., (2018). 'Representative co-production: broadening the scope of the public service logic'. *Public Management Review* 1–24. <https://doi.org/10.1080/14719037.2018.1487575>
- Ewert, B., Evers, A., (2014). 'An Ambiguous Concept: On the Meanings of Co-production for Health Care Users and User Organizations?' *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations* 25, 425–442. <https://doi.org/10.1007/s11266-012-9345-2>
- Fan, R.P., (2007). 'Confucian Familism and Its Bioethical Implications'. In: Lee, S.C., (ed.). *'The Family, Medical Decision-making, and Biotechnology'* (1. Aufl. ed., Philosophy and medicine). Dordrecht: Springer-Verlag, pp.15-25.
- Fan, R.P., (2015). 'Informed Consent: Why Family-Oriented?'. In: Fan, R.P., (ed.). *'Family-oriented Informed Consent: East Asian and American perspectives'*. (Philosophy and Medicine; v. 121). Cham: Springer, pp. 3-23.
- Fang, L., (2018). *The Chinese Health System in Transition*, Singapore: Springer Singapore Pte. Limited.
- Farrell, C., (2004). *Patient and public involvement in health: the evidence for policy implementation: a summary of the results of the Health in Partnership research programme*. London: Department of Health.
- Finnegan, R., (2006). Using Documents, in: Sapsford, R., Jupp, V., (ed). *Data collection and analysis, Second edition*. Los Angeles; London: SAGE Publications in association with the Open University, pp.138-152. <https://dx-doi-org.ezproxy.is.ed.ac.uk/10.4135/9781849208802.n6>
- Fischer, F., (2006). Participatory Governance as Deliberative Empowerment. *American review of public administration*, 36(1), pp.19–40. <https://doi-org.ezproxy.is.ed.ac.uk/10.1177/0275074005282582>
- Fischer, F., (2012). 'Participatory governance: from theory to practice'. in Levi-Faur, D (ed.). *The Oxford Handbook of Governance*. Oxford: Oxford University Press, pp. 458-566. Retrieved 16 Jun. 2020, from <https://www-oxfordhandbooks-com.ezproxy.is.ed.ac.uk/view/10.1093/oxfordhb/9780199560530.001.0001/oxfordhb-9780199560530-e-32>.
- Flick, U., (2014). *The SAGE Handbook of Qualitative Data Analysis*. London, UK: SAGE Publications.
- Florin, D., Dixon, J., (2004). 'Public involvement in health care'. *BMJ* 328 (7432), 159-161.
- Fotaki, M., (2011). 'Towards developing new partnerships in public services'. *Public Administration* 89, 933–955. <https://doi.org/10.1111/j.1467-9299.2010.01879.x>
- Fotaki, M., (2013). 'Is patient choice the future of health care systems?' *International journal of health policy and management* 1, 121–123.
- Fotaki, M., Roland, M., Boyd, A., McDonald, R., Scheaff, R., Smith, L., (2008). 'What benefits will choice bring to patients? Literature review and assessment of implications'. *Journal of Health Services Research & Policy* 13, 178–184. <https://doi.org/10.1258/jhsrp.2008.007163>
- France, E.F., Wyke, S., Ziebland, S., Entwistle, V.A., Hunt, K., (2011). 'How personal experiences feature in women's accounts of use of

- information for decisions about antenatal diagnostic testing for foetal abnormality'. *Social Science & Medicine* 72, 755–762. <https://doi.org/10.1016/j.socscimed.2010.11.031>
- Fredriksson, M., Tritter, J.Q., (2017). 'Disentangling patient and public involvement in healthcare decisions: why the difference matters'. *Social Health Illn* 39, 95–111. <https://doi.org/10.1111/1467-9566.12483>
- Freeman, R., (2000). *The politics of health in Europe*. Manchester University Press.
- Freidson, E., (1970a). *Profession of Medicine: a study of the sociology of applied knowledge*, New York: Harper& Row: Dodd Mead.
- Freidson, E., (1970b). *Professional Dominance: The Social Structure of Medical Care*. New York; Chicago: Atherton Press.
- Fumagalli, L.P., Radaelli, G., Lettieri, E., Bertele, P., Masella, C., (2015). 'Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships'. *Health Policy* 119, 384–394. <https://doi.org/10.1016/j.healthpol.2014.10.017>
- Fung, A., (2003). Survey Article: Recipes for Public Spheres: Eight Institutional Design Choices and Their Consequences. *The journal of political philosophy*, 11(3), pp.338–367. <https://doi-org.ezproxy.is.ed.ac.uk/10.1111/1467-9760.00181>
- Fung, A., (2015). 'Putting the Public Back into Governance: The Challenges of Citizen Participation and Its Future'. *Public Administration Review* 75, 513–522. <https://doi.org/10.1111/puar.12361>
- Gabriel, Y., Lang, T., (2006). 'The Consumer as Chooser', in. Gabriel, Y., Lang, T., *The Unmanageable Consumer*. London: SAGE Publications Ltd, pp. 25-43.
- Gaston, C.M., Mitchell, G., (2005). 'Information-giving and decision-making in patients with advanced cancer: A systematic review'. *Social Science & Medicine* 61, 2252–2264. <https://doi.org/10.1016/j.socscimed.2005.04.015>
- General Office of State Council (2009) *The Working Arrangements of Five Key Health-care Reforms in 2009* [2009] 75 (Yiliao Weisheng Tizhi Wuxiang Zhongdian Gaige 2009nian Gongzuo An'pai). Available at: http://www.gov.cn/zhengce/content/2009-07/23/content_6221.htm (Accessed: 15 June 2020).
- General Office of State Council (2013a) *The Guidance of Government Purchasing Services from Social organisations* [2013] 96 (Guowuyuan Bangongting Guanyu Zhengfu Xiang Shehui Liliang Goumai Wufu de Zhidao Yijian). Available at: http://www.gov.cn/zwgk/2013-09/30/content_2498186.htm (Accessed: 16 June 2020).
- General Office of State Council (2013b) *The Notice of the Working Arrangements of Strengthening Health System Reforms in 2013* [2013] 80 (Guowuyuan Bangongting Guanyu Yinfa Shenhua Yiyao Weisheng Tizhi Gaige 2013nian Zhuyao Gongzuo An'pai de Tongzhi). Available at: http://www.gov.cn/zhengce/content/2013-07/24/content_6095.htm (Accessed: 15 June 2020).
- General Office of State Council (2015a) *The Policy Initiatives of Promoting Social Investment in Health Service Provision* [2015] 45 (Guanyu Cujin Shehui Banyi Jiakuai Fazhan de Ruogan Zhengce Cuoshi). Available at: http://www.gov.cn/zhengce/content/2015-06/15/content_9845.htm (Accessed: 15 June 2020).

General Office of State Council (2015b) *Suggestions of Strengthening the Party Building in Social Organisations (Trial)* (Guanyu Jiaqiang Shehui Zuzhi Dangdejian she Gongzuo de Yijian(Shixing)). Available at: http://www.gov.cn/xinwen/2015-09/28/content_2939936.htm (Accessed: 16 June 2020).

General Office of State Council (2015c) *The Instructions and Guidance of Promoting Institutional Design of Hierarchical Medical System [2015]* 70 (Guowuyuan Bangongting Guanyu Tuijin Fenji Zhenliao Zhidu Jianshe de Zhidao Yijian) Available at http://www.gov.cn/zhengce/content/2015-09/11/content_10158.htm (Accessed: 19 June 2020)

Glenister, D., (1994). 'Patient participation in psychiatric services: a literature review and proposal for a research strategy'. *Journal of Advanced Nursing* 19, 802–811. <https://doi.org/10.1111/j.1365-2648.1994.tb01153.x>

Greener, I., (2008). 'Markets in the public sector: when do they work, and what do we do when they don't?' *Policy & Politics* 36, 93–108.

Greenhalgh, T., (2009). 'Chronic illness: beyond the expert patient'. *BMJ: British Medical Journal* 338, 629–631.

Greenhalgh, T., Humphrey, C. Woodard, F., (2011). 'User involvement- a story of our time.', in Greenhalgh, T., Humphrey, C., Woodard, F., (ed.). *User Involvement in Health Care*. Wiley-Blackwell, pp. 1-9.

Guadagnoli, E., Ward, P., (1998). 'Patient participation in decision-making'. *Social Science & Medicine* 47, 329–339.

Guo, S., (2013). *Chinese politics and government: power, ideology, and organization*. London: Routledge.

Haarmann, A., (2018). *The Evolution and Everyday Practice of Collective Patient Involvement in Europe*. Springer International Publishing, Cham. <https://doi.org/10.1007/978-3-319-64595-7>

Haarmann, A., Klenk, T., Weyrauch, P., (2010). 'Exit, Choice – and What About Voice? Public involvement in corporatist healthcare states'. *Public Management Review* 12, 213–231. <https://doi.org/10.1080/14719031003616289>

Hammersley, M., (1992). *What's wrong with ethnography?: methodological explorations*. London: Routledge.

Haxby, Elizabeth, Haxby, E., Hunter, David, Hunter, D., Jaggar, Siân, Jaggar, S., (2010). *An Introduction to Clinical Governance and Patient Safety*. Oxford: Oxford University Press. <https://doi.org/10.1093/acprof:oso/9780199558612.001.0001>

He, A.J., (2014). 'The doctor–patient relationship, defensive medicine and overprescription in Chinese public hospitals: Evidence from a cross-sectional survey in Shenzhen city'. *Social Science & Medicine* 123, 64–71. <https://doi.org/10.1016/j.socscimed.2014.10.055>

He, B., Warren, M.E., (2011). 'Authoritarian Deliberation: The Deliberative Turn in Chinese Political Development'. *Perspectives on Politics* 9, 269–289. <https://doi.org/10.1017/S1537592711000892>

Healthtalk.org (no date) *Real People, Real life experiences*. Available at: <https://www.healthtalk.org/> (Accessed: 15 June 2020).

Hesketh, T. & Zhu, W. X., (1997). Health in china: From Mao to market reform. *BMJ*, 314(7093), p.1543.

Hilton, B.A., (1994). 'The 1993 Schering Lecture: Family decision-making processes about early stage breast cancer treatment'. *Canadian Oncology Nursing Journal* 4, 9–16. <https://doi.org/10.5737/1181912x41916>

- Hirschman, A.O., (1970). *Exit, voice and loyalty: responses to decline in firms, organizations, and states*. Cambridge, Mass.: Harvard University Press.
- Hogg, C. (Christine), (2009). *Citizens, consumers, and the National Health Service: capturing voices*. Basingstoke England; New York: Palgrave Macmillan.
- Hood, C., (1991). 'A public management for all seasons?' *Public Administration* 69, 3–19. <https://doi.org/10.1111/j.1467-9299.1991.tb00779.x>
- Howell, J. (2012) 'Civil Society in China', in: *The Oxford Handbook of Civil Society*. Oxford: Oxford University Press, pp. 160–170. <https://doi.org/10.1093/oxfordhb/9780195398571.013.0013>
- Howell, J., Duckett, J., (2019). 'Reassessing the Hu–Wen Era: A Golden Age or Lost Decade for Social Policy in China?' *The China Quarterly* 237, 1–14. <https://doi.org/10.1017/S0305741018001200>
- Hsiao, W.C., Hu, L., (2010). 'The state of medical professionalism in China: Past, present, and future'. in Alford., WP., Kirby, W., Winston, K. (ed.) *Prospects for the Professions in China*. Routledge Taylor & Francis Group, pp. 111–128 <https://doi.org/10.4324/9780203843024>
- Hu., A. G., (2013). *Hu Angang: Why People's Society is better than Civil Society?* Available at: <https://opinion.huanqiu.com/article/9CaKrnJBpTc> (Accessed: 6 January, 2021)
- Huang, Y., (2013). *Governing health in contemporary China*. New York: Routledge.
- Huang, Y., (2019). 'At the Mercy of the State: Health Philanthropy in China'. *Voluntas* 30, 634–646. <https://doi.org/10.1007/s11266-018-9960-7>
- Hubbard, G., Illingworth, N., Rowa-Dewar, N., Forbat, L., Kearney, N., (2010). 'Treatment decision-making in cancer care: the role of the carer'. *Journal of Clinical Nursing* 19, 2023–2031. <https://doi.org/10.1111/j.1365-2702.2009.03062.x>
- Hui, E.C., (2010). 'The Contemporary Healthcare Crisis in China and the Role of Medical Professionalism'. *Journal of Medicine and Philosophy* 35, 477–492. <https://doi.org/10.1093/jmp/jhq031>
- Hunter, D., (2004). 'A structural perspective on health care reform'. *Journal of Health Services Research & Policy* 9, 51–53. <https://doi.org/10.1258/135581904322716120>
- Investigator of Dingxiang (2016) 43% Health professionals thought the relationship was very nervous. Available at: <https://vote.dxy.cn/report/dxy/id/505240> (Accessed: 16 June 2020).
- Jaspers, S., Steen, T., (2018). 'Realizing public values: enhancement or obstruction? Exploring value tensions and coping strategies in the co-production of social care'. *Public Management Review* 0, 1–22. <https://doi.org/10.1080/14719037.2018.1508608>
- Jian, W., Figueroa, J., Woskie, L., Yao, X., Zhou, Y., Li, Z., Li, C., Yao, L., Yip, W.C., (2019). 'Quality of care in large Chinese hospitals: an observational study'. *BMJ Qual Saf* bmjqs-2018-008938. <https://doi.org/10.1136/bmjqs-2018-008938>
- Jie, C., (2006). 'The NGO Community in China: Expanding Linkages With Transnational Civil Society and Their Democratic Implications'. *chinaperspectives* 2006, 29–40. <https://doi.org/10.4000/chinaperspectives.3083>
- Jo, H.S., Park, K., Jung, S.M., (2019). 'A scoping review of consumer needs for cancer information'. *Patient Education and Counseling* 102, 1237–1250. <https://doi.org/10.1016/j.pec.2019.02.004>

- Jo, S., Nabatchi, T., (2018). 'Coproducing healthcare: individual-level impacts of engaging citizens to develop recommendations for reducing diagnostic error'. *Public Management Review* 1–22. <https://doi.org/10.1080/14719037.2018.1487577>
- Joshi, A., Moore, M., (2004). 'Institutionalised co-production: unorthodox public service delivery in challenging environments'. *Journal of Development Studies* 40, 31–49.
- Jost, T., (2007). *Health Care at Risk: A Critique of the Consumer-Driven Movement*. Duke University Press. <https://doi.org/10.1215/9780822390541>
- Journal of People's Political Consultative Conference (2015). *Embracing the thirtieth year of Chinese health care reforms (Woguo Yigai Yinglai er'li Zhinian)*. Available at: http://www.xinhuanet.com/politics/2015-02/11/c_127483532.htm (Accessed : 22 June, 2020)
- Jung, T., (2010). 'Citizens, co-producers, customers, clients, captives? A critical review of consumerism and public services'. *Public Management Review* 12, 439–446. <https://doi.org/10.1080/14719031003787940>
- Kaarbo, J., Beasley, R.K., (1999). 'A practical guide to the comparative case study method in political psychology'. *Political Psychology* 20, 369–391.
- Khangura, S., Bennett, C., Stacey, D., O'Connor, A.M., (2008). 'Personal stories in publicly available patient decision aids'. *Patient Education and Counseling* 73, 456–464. <https://doi.org/10.1016/j.pec.2008.07.035>
- Kolasa, K., Dohnalik, J., Borek, E., Siemiątkowski, M., Ścibiorski, C., (2014). 'The paradox of public participation in the healthcare in Poland—What citizens want, and what they think'. *Health Policy* 118, 159–165.
- Kooiman, J., (2003). *Governing as Governance*. London; Thousand Oaks, Calif.: SAGE.
- Kornreich, Y., Vertinsky, I., Potter, P.B., (2012). 'Consultation and Deliberation in China: The Making of China's Health-Care Reform'. *The China Journal* 68, 176–203. <https://doi.org/10.1086/666583>
- Kymlicka, W., Norman, W., (1994). 'Return of the Citizen: A Survey of Recent Work on Citizenship Theory'. *Ethics* 104, 352–381. <https://doi.org/10.1086/293605>
- Laidsaar-Powell, R., Butow, P., Bu, S., Charles, C., Gafni, A., Fisher, A., Juraskova, I., (2016). 'Family involvement in cancer treatment decision-making: A qualitative study of patient, family, and clinician attitudes and experiences'. *Patient Education and Counseling* 99, 1146–1155. <https://doi.org/10.1016/j.pec.2016.01.014>
- Lane, J. (2000), 'Public goods', in Badie, B., Berg-Schlosser, D & Morlino, L (ed), *International encyclopedia of political science*, Thousand Oaks, CA: SAGE Publications, Inc., pp. 2159-2161. <https://doi.org/10.4135/9781412959636.n494>.
- Langberg, E.M., Dyhr, L., Davidsen, A.S., (2019). 'Development of the concept of patient-centredness – A systematic review'. *Patient Education and Counseling* 102, 1228–1236. <https://doi.org/10.1016/j.pec.2019.02.023>
- Lawrence, C., (2008). 'Patient'. *The Lancet* 371, 21. [https://doi.org/10.1016/S0140-6736\(08\)60055-0](https://doi.org/10.1016/S0140-6736(08)60055-0)
- Le Grand, J., (2003). *Motivation, agency, and public policy: of knights and knaves, pawns and queens*. Oxford: Oxford University Press.
- Lee, S.K.C., Knobf, M.T., (2016). 'Family involvement for breast cancer

- decision making among Chinese-American women: Family involvement in treatment decision making'. *Psycho-Oncology* 25, 1493–1499. <https://doi.org/10.1002/pon.3989>
- Levi-Faur, D., (2012). 'From big government to big governance?' in Levi-Faur, D. (ed.). *The Oxford Handbook of Governance*. Oxford: Oxford University Press, pp 4-17.
- Li, X., Krumholz, H.M., (2019). 'What does it take to improve nationwide healthcare quality in China?' *BMJ Qual Saf* bmjqs-2019-009839. <https://doi.org/10.1136/bmjqs-2019-009839>
- Li, Y., Xu, J., Wang, F., Wang, B., Liu, L., Hou, W., Fan, H., Tong, Y., Zhang, J., Lu, Z., (2012). 'Overprescribing In China, Driven By Financial Incentives, Results In Very High Use Of Antibiotics, Injections, And Corticosteroids'. *Health Affairs* 31, 1075–1082. <https://doi.org/10.1377/hlthaff.2010.0965>
- Lieberthal, K., Lampton, D.M., others, (1992). *Bureaucracy, politics, and decision making in post-Mao China*. Berkeley: University of California Press.
- Lindsay, C., Pearson, S., Batty, E., Cullen, A.M., Eadson, W., (2018). 'Co-production as a route to employability: Lessons from services with lone parents'. *Public Administration* 96, 318–332. <https://doi.org/10.1111/padm.12408>
- Lipsky, M., (1980). *Street-level bureaucracy: dilemmas of the individual in public services*. New York: Russell Sage Foundation.
- Liu, Yuanli et al., (2006). Health care in China: The role of non-government providers. *Health policy (Amsterdam)*, 77(2), pp.212–220.
- Long, J., Zeng, F., Wang, L., Yi, C., Chen, Q., others, (2020). 'Gender-specific cardiovascular outcomes in patients undergoing percutaneous coronary intervention in Chinese populations'. *BMC Cardiovascular Disorder*, Vol. 20 (15), pp. 991-998.
- Lopes, E., Carter, D. & Street, J., (2015). 'Power relations and contrasting conceptions of evidence in patient-involvement processes used to inform health funding decisions in Australia'. *Social Science & Medicine*, 135, pp.84–91.
- Lowndes, V., Pratchett, L., Stoker, G., (2001a). 'Trends In Public Participation: Part 1 - Local Government Perspectives'. *Public Administration* 79, 205–222. <https://doi.org/10.1111/1467-9299.00253>
- Lowndes, V., Pratchett, L., Stoker, G., (2001b). 'Trends in Public Participation: Part 2 – Citizens' Perspectives'. *Public Administration* 79, 445–455. <https://doi.org/10.1111/1467-9299.00264>
- Lu, X., (2016). *The policies of registering social organisations directly: the past and the present*. (Shehuizuzhi zhijie dengji zhengce de qianshijinsheng). Available at: <http://www.chinadevelopmentbrief.org.cn/news-18847.html> (Accessed: 6 January 2021)
- Lupton, D., (1997). 'Consumerism, reflexivity and the medical encounter'. *Social science & medicine* 45, 373–381.
- Lv, A., (2015). *Explaining health policy change in China between 2003 and 2009: actors, contexts and institutionalisation*. Ph.D. University of Glasgow. Available at: <http://theses.gla.ac.uk/6651/> (Accessed: 17 June 2020)
- Ma, W., (2015). Jianxing Yu and Sujian Guo, eds., Civil Society and Governance in China. *Journal of Chinese Political Science*, 20(4), pp.493–494.
- Marshall, T.H. (Thomas H.), (1963). *Citizenship and social class*. University

- Matthews, F., (2012). *Governance and State Capacity*. Oxford: Oxford University Press.
<https://doi.org/10.1093/oxfordhb/9780199560530.013.0020>
- Maxwell, J., (2009). 'Designing a Qualitative Study', in: Bickman., L; Rog., Debra. (ed.) *The SAGE Handbook of Applied Social Research Methods*. Thousand Oaks: SAGE Publications, Inc. pp. 214–253.
<https://doi.org/10.4135/9781483348858.n7>
- Mead, N., Bower, P., (2000). 'Patient-centredness: a conceptual framework and review of the empirical literature'. *Social science & medicine* 51, 1087–1110.
- Meng, Q., Shi, G., Yang, H., Gonzalez-Block, M., Blas, E., others, (2004). *Health policy and systems research in China*. UNICEF/UNDP/World Bank/WHO Special programme for research training in tropical diseases (TDR). China: China Health Economic Institute, WHO.
- Meng, Q., Xu, L., Zhang, Y., Qian, J., Cai, M., Xin, Y., Gao, J., Xu, K., Boerma, J.T., Barber, S.L., (2012). 'Trends in access to health services and financial protection in China between 2003 and 2011: a cross-sectional study'. *The Lancet* 379, 805–814.
[https://doi.org/10.1016/S0140-6736\(12\)60278-5](https://doi.org/10.1016/S0140-6736(12)60278-5)
- Meng, Q., Yang, H., Chen, W., Sun, Q., Liu, X., (2015). 'People's Republic of China Health System Review'. *Health Systems in Transition*, 5 (7).
- Menon, Sumytra, Entwistle, Vikki A, Campbell, Alastair V, & Van Delden, Johannes J. M. (2020). Some Unresolved Ethical Challenges in Healthcare Decision-Making: Navigating Family Involvement. *Asian Bioethics Review*, 12(1), 27-36.
- Ministry of Health (2005). *The Notice regarding 'Indications of Hospital Management Evaluation' (Trials) (Guanyu yinfa 'yiyuanguanli pingjia zhinan (shixing)'de tongzhi)*, Available at: <https://wenku.baidu.com/view/2561c1f0001ca300a6c30c22590102020740f2bd.html> (Accessed: 10 January 2021)
- Ministry of Health (2008). *An Analysis Report of National Health Services Survey in China, 2008*, Available at: <http://www.nhc.gov.cn/mohwsbwstjxxzx/s8211/201009/49165.shtml> (Accessed: 12 December 2020)
- Mockford, C., Staniszewska, S., Griffiths, F., Herron-Marx, S., (2012). 'The impact of patient and public involvement on UK NHS health care: a systematic review'. *International Journal for Quality in Health Care* 24, 28–38. <https://doi.org/10.1093/intqhc/mzr066>
- Mullen, C., Hughes, D., Vincent-Jones, P., (2011). 'The Democratic Potential of Public Participation: Healthcare Governance in England'. *Social & Legal Studies* 20, 21–38. <https://doi.org/10.1177/0964663910391349>
- Munro, N., (2012). Connections, Paperwork or Passivity: Strategies of Popular Engagement with the Chinese Bureaucracy. *The China Journal*, 68, 147-175, 271.
doi:<http://dx.doi.org.ezproxy.is.ed.ac.uk/10.1086/666576>
- Munro, N., (2013). Chinese Strategies for Getting Health Care: Guanxi and its Alternatives. Working Paper. University of Strathclyde, Glasgow, UK.
- Munro, N., Duckett, J., (2016). 'Explaining public satisfaction with health-care systems: findings from a nationwide survey in China'. *Health Expectations* 19, 654–666. <https://doi.org/10.1111/hex.12429>
- Nabatchi, T., Sancino, A., Sicilia, M., (2017). 'Varieties of Participation in Public Services: The Who, When, and What of Coproduction'. *Public*

National Health and Family Planning Commission of China (2013) *Strengthening ethics of health care industry with nine forbidden behaviours* (Jiaqiang Yiliaoweisheng Hangyejianshe 'jiubuzhun'). Available at: <https://baike.baidu.com/item/%E5%8A%A0%E5%BC%BA%E5%8C%BB%E7%96%97%E5%8D%AB%E7%94%9F%E8%A1%8C%E9%A3%8E%E5%BB%BA%E8%AE%BE%E2%80%9C%E4%B9%9D%E4%B8%8D%E5%87%86%E2%80%9D/12756539> (Accessed: 11 December 2020).

National Health and Family Planning Commission of China (2013). *An Analysis Report of National Health Services Survey in China, 2013*. Available at: <http://www.nhc.gov.cn/mohwsbwstjxxzx/s8211/201610/9f109ff40e9346fca76dd82cecf419ce.shtml> (Accessed: 12 December 2020).

National Health Commission of China (2016) *Regulations of Health Care Management* (No. 10). Available at: <http://www.nhc.gov.cn/xxgk/pages/viewdocument.jsp?dispatchDate=&staticUrl=/fzs/s3576/201610/ae125f28eef24ca7aac57c8ec530c6d2.shtml&weihao=%E7%AC%AC10%E5%8F%B7%E5%A7%94%E4%BB%A4&utitle=%E5%8C%BB%E7%96%97%E8%B4%A8%E9%87%8F%E7%AE%A1%E7%90%86%E5%8A%9E%E6%B3%95&topic=&publishedOrg=%E6%B3%95%E5%88%B6%E5%8F%B8&indexNum=000013610/2016-00218&manuscriptId=ae125f28eef24ca7aac57c8ec530c6d2> (Accessed: 16 June 2020).

National Health Commission of China (2018) *Working Initiatives of Improving Health Care Quality [2017] 73* (Jinyibu Gaishan Yiliao Fuwu Xingdong Jihua). Available at: <http://www.nhc.gov.cn/cms-search/xxgk/getManuscriptXxgk.htm?id=9df87fced4da47b0a9f8e1ce9fbc7520> (Accessed: 16 June 2020).

National People's Congress of China (1999) *The Law of Practising Physicians of China* (Zhonghua Renmin Gongheguo Zhiye Yishifa). Available at: http://www.gov.cn/banshi/2005-08/01/content_18970.htm (Accessed: 15 June 2020).

Negro, G., (2017). *The Internet in China*. Cham: Springer International Publishing: Imprint: Palgrave Macmillan. <https://doi.org/10.1007/978-3-319-60405-3>

Osborne, D., (1993). 'Reinventing Government'. *Public Productivity & Management Review* 16, 349–356. <https://doi.org/10.2307/3381012>

Osborne, S.P., (2010). *The New Public Governance: Emerging Perspectives on the Theory and Practice of Public Governance*. Abingdon; New York: Routledge.

Osborne, S.P., Radnor, Z., Nasi, G., (2013). 'A New Theory for Public Service Management? Toward a (Public) Service-Dominant Approach'. *The American Review of Public Administration* 43, 135–158. <https://doi.org/10.1177/0275074012466935>

Osborne, S.P., Radnor, Z., Strokosch, K., (2016). 'Co-Production and the Co-Creation of Value in Public Services: A suitable case for treatment?' *Public Management Review* 18, 639–653. <https://doi.org/10.1080/14719037.2015.1111927>

Ostrom, E., (1972). 'Metropolitan Reform: Propositions Derived from Two Traditions'. *Social Science Quarterly* 53, 474–493.

Ostrom, E., (1996). 'Crossing the great divide: Coproduction, synergy, and

- development'. *World Development* 24, 1073–1087.
[https://doi.org/10.1016/0305-750X\(96\)00023-X](https://doi.org/10.1016/0305-750X(96)00023-X)
- Pan, J., Liu, D., Ali, S., (2015). 'Patient dissatisfaction in China: What matters'. *Social Science & Medicine* 143, 145–153.
<https://doi.org/10.1016/j.socscimed.2015.08.051>
- Papadopoulos, Y., Benz, A. (Ed.), (2006). *Governance and democracy: comparing national, European and international experiences*. London; New York: Routledge.
- Parkinson, J., (2003). 'Legitimacy Problems in Deliberative Democracy'. *Political Studies* 51, 180–196. <https://doi.org/10.1111/1467-9248.00419>
- Parks, R.B., Baker, P.C., Kiser, L., Oakerson, R., Ostrom, E., Ostrom, V., Percy, S.L., Vandivort, M.B., Whitaker, G.P., Wilson, R., (1981). 'Consumers as Coproducers of Public Services: Some Economic and Institutional Considerations'. *Policy Studies Journal* 9.
- Participedia (1992) *Municipal Health Councils (Brazil)*. Available at: <https://participedia.net/case/15> (Accessed: 24 June 2020).
- Participedia (2005) *Citizens' Dialogue on Public Health Goals in Canada (2005)*. Available at: <https://participedia.net/case/630> (Accessed: 24 June 2020).
- Participedia (2016) *St. Michael's Residents' Health Services Panel*. Available at: <https://participedia.net/case/4697> (Accessed: 24 June 2020).
- Pasick, R.J., Burke, N.J., (2008). 'A Critical Review of Theory in Breast Cancer Screening Promotion across Cultures'. *Annual Review of Public Health* 29, 351–368.
<https://doi.org/10.1146/annurev.publhealth.29.020907.143420>
- Pateman, C., (2012). 'APSA Presidential Address: Participatory Democracy Revisited'. *Perspectives on politics* 10, 7–19.
<https://doi.org/10.1017/S1537592711004877>
- Patient Rights (Scotland) Act 2011, asp 5*. Scotland. Available at: <http://www.legislation.gov.uk/asp/2011/5/contents> (Accessed: 15 June 2020).
- Pekonen, A., Eloranta, S., Stolt, M., Virolainen, P., Leino-Kilpi, H., (2019). 'Measuring patient empowerment – A systematic review'. *Patient Education and Counseling* S0738399119304768.
<https://doi.org/10.1016/j.pec.2019.10.019>
- Pestoff, V., Brandsen, T., Verschuere, B., (2013). *New Public Governance, the Third Sector and Co-Production*. Routledge.
- Peters, B.G., Pierre, J., (1998). 'Governance without government? Rethinking public administration'. *Journal of public administration research and theory* 8, 223–243.
- Peters, B.G., Pierre, J., (2016). *Comparative Governance: Rediscovering the Functional Dimension of Governing*. Cambridge: Cambridge University Press. <https://doi.org/10.1017/CBO9781316681725>
- Phillips, S.D., (2012). 'The New Citizenship and Governance: Alternative Intersections'. in: Levi-Faur, D. (ed.). *The Oxford Handbook of Governance*. Oxford: Oxford University Press, pp. 485–497.
<https://doi.org/10.1093/oxfordhb/9780199560530.013.0034>
- Pierre, J., & Peters, B. G. (2020). *Governance, politics and the state*. UK: Red Globe Press.
- Pierson, P., (2000). 'Increasing Returns, Path Dependence, and the Study of Politics'. *The American Political Science Review* 94, 251–267.
- Pieterse, A.H., Finset, A., (2019). 'Shared decision making—Much studied,

- much still unknown'. *Patient Education and Counseling* 102, 1946–1948. <https://doi.org/10.1016/j.pec.2019.09.006>
- Prior, L., (2003). 'Belief, knowledge and expertise: the emergence of the lay expert in medical sociology'. *Sociology of health & illness* 25, 41–57.
- Putnam, R.D., (2000). *Bowling alone: the collapse and revival of American community*. New York; London: Simon & Schuster.
- Ramesh, M., Wu, X., Howlett, M., (2015). 'Second Best Governance? Governments and Governance in the Imperfect World of Health Care Delivery in China, India and Thailand in Comparative Perspective'. *Journal of Comparative Policy Analysis: Research and Practice* 17, 342–358. <https://doi.org/10.1080/13876988.2014.889903>
- Rhodes, R. a. W., (1994). 'The Hollowing Out of the State: The Changing Nature of the Public Service in Britain'. *The Political Quarterly* 65, 138–151. <https://doi.org/10.1111/j.1467-923X.1994.tb00441.x>
- Rhodes, R.A.W., (1996). 'The new governance: governing without government'. *Political studies* 44, 652–667.
- Ritchie, J., Lewis, J., Lewis, P. of S.P.J., Nicholls, C.M., Ormston, R., (2014). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Second edition. Los Angeles: SAGE.
- Robson, C., (2002). *Real world research: a resource for social scientists and practitioner-researchers*, Second edition. ed. Oxford, UK; Malden, Mass.: Blackwell Publishers.
- Ron, A., (2012). *Modes Of Democratic Governance*. Oxford: Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780199560530.013.0033>
- Rosén, P., Anell, A., Hjortsberg, C., (2001). 'Patient views on choice and participation in primary health care'. *Health policy* 55, 121–128.
- Rosenau, J.N., (1995). 'Governance in the Twenty-first Century'. *Global Governance* 1, 13–43. <https://doi.org/10.1163/19426720-001-01-90000004>
- Rosenberg, D., Hillborg, H., (2016). 'Systematizing Knowledge of User Influence – A Study of User Advisory Boards in Substance Abuse and Mental Health Services'. *Social Policy & Administration* 50, 336–352. <https://doi.org/10.1111/spol.12113>
- Rosentraub, M.S., Sharp, E.B., (1981). 'Consumers as producers of social services: coproduction and the level of social services'. *Southern Review of Public Administration*, 39, pp.502-539.
- Rowe, R., Shepherd, M., (2002). 'Public Participation in the New NHS: No Closer to Citizen Control?' *Social Policy & Administration* 36, 275–290. <https://doi.org/10.1111/1467-9515.00251>
- Rubin, H., Rubin, I., (2005). 'Chapter 5 Conversational Partnership', in: Rubin, H., Rubin, I., (ed). *Qualitative Interviewing (2nd ed.): The Art of Hearing Data*. Thousand Oaks: SAGE Publications, Inc., pp. 79-107. <https://dx-doi-org.ezproxy.is.ed.ac.uk/10.4135/9781452226651.n5>
- Sabadosa, K.A., Batalden, P.B., (2014). 'The interdependent roles of patients, families and professionals in cystic fibrosis: a system for the coproduction of healthcare and its improvement'. *BMJ Quality & Safety* 23, i90–i94. <https://doi.org/10.1136/bmjqs-2013-002782>
- Saich, T., (2001). *Governance and politics of China*. New York: Palgrave.
- Schain, W.S., (1980). 'Patients' rights in decision making: the case for personalism versus paternalism in health care'. *Cancer* 46, 1035. [https://doi.org/10.1002/1097-0142\(19800815\)46:4+<1035::AID-CNCR2820461329>3.0.CO](https://doi.org/10.1002/1097-0142(19800815)46:4+<1035::AID-CNCR2820461329>3.0.CO)
- Shen, C., Jin, J., Zou, H., others, (2012). 'Fiscal decentralization in China: history, impact, challenges and next steps'. *Annals of Economics and*

Finance 13, 1–51.

- Shim, J.K., (2010). 'Cultural health capital a theoretical approach to understanding health care interactions and the dynamics of unequal treatment'. *Journal of Health and Social Behavior* 51, 1–15.
- Silber, J.H. et al., (2020). 'Comparing outcomes and costs of medical patients treated at major teaching and non-teaching hospitals: a national matched analysis'. *Journal of general internal medicine*, 35(3). 743-752.
- Sillence, E., Briggs, P., Harris, P.R., Fishwick, L., (2007). 'How do patients evaluate and make use of online health information?' *Social Science & Medicine* 64, 1853–1862. <https://doi.org/10.1016/j.socscimed.2007.01.012>
- Simmons, R., Birchall, J., (2005). 'A Joined-up Approach to User Participation in Public Services: Strengthening the "Participation Chain."' *Social Policy & Administration* 39, 260–283.
- Sintomer, Y., Herzberg, C., RöCke, A., (2008). 'Participatory Budgeting in Europe: Potentials and Challenges'. *International Journal of Urban and Regional Research* 32, 164–178. <https://doi.org/10.1111/j.1468-2427.2008.00777.x>
- Solinger, D., (2006) 'Interviewing Chinese people: from high-level officials to the unemployed'. in: Thøgersen, S., Heimer, M. (ed.) *Doing Fieldwork in China*. Copenhagen: NIAS Press, pp. 153-167.
- State Council (2002) *The Regulation of Medical Accident Management (Yiliao Shigu Chuli Tiaoli)*. Available at: http://www.gov.cn/banshi/2005-08/02/content_19167.htm (Accessed: 15 June 2020).
- State Council (2013) *State Council regarding the Suggestions of Promoting Health Services [2013] 40 (Guowuyuan Guanyu Cujin Jiankang Fuwuye Fazhan de Ruogan Yijian)*. Available at: http://www.gov.cn/zhengce/content/2013-10/18/content_6067.htm (Accessed: 15 June 2020).
- Stewart, M., (2003). *Patient-centered medicine: transforming the clinical method, Second edition*. Abingdon, Oxon, U.K.: Radcliffe Medical Press.
- Stoker, G., (1998). 'Governance as theory: five propositions'. *International Social Science Journal* 50, 17–28. <https://doi.org/10.1111/1468-2451.00106>
- Strull, W.M., Lo, B., Charles, G., (1984). 'Do patients want to participate in medical decision making?' *Jama* 252, 2990–2994.
- Su., L.Y., Wang., Y. (2016) 'China's 'central-local interaction' decision-making', *Journal of Public Management (Quarterly)*, Vol.13 (3), pp.1-11.
- Sun, J., Hu, G., Ma, J., Chen, Y., Wu, L., Liu, Q., Hu, J., Livoti, C., Jiang, Y., Liu, Y., (2017). 'Consumer satisfaction with tertiary healthcare in China: findings from the 2015 China National Patient Survey'. *International Journal for Quality in Health Care*. <https://doi.org/10.1093/intqhc/mzw160>
- Sun, G., & Zhang, X.P., (2010). 'Length of health consultation: evidence from an investigation in the eastern, middle and western parts of China'. *Chinese Health Care Management*, Vol.1, pp. 60-62.
- Süssmuth-Dyckerhoff, C., Then, F., (2017). 'China's Healthcare Reform: Status and Outlook', in: Burns, L.R., Liu, G.G. (ed.), *China's Healthcare System and Reform*. Cambridge: Cambridge University Press, pp. 137–149. <https://doi.org/10.1017/9781316691113.007>
- Sutherland, H.J., Llewellyn-Thomas, H.A., Lockwood, G.A., Tritchler, D.L.,

- Till, J.E., (1989). 'Cancer patients: their desire for information and participation in treatment decisions'. *Journal of the Royal Society of Medicine* 82, 260–263.
- Tam Ashing, K., Padilla, G., Tejero, J., Kagawa-Singer, M., (2003). 'Understanding the breast cancer experience of Asian American women'. *Psycho-Oncology* 12, 38–58. <https://doi.org/10.1002/pon.632>
- Tam, W., (2010). 'Privatising Health Care in China: Problems and Reforms'. *Journal of Contemporary Asia* 40, 63–81. <https://doi.org/10.1080/00472330903270700>
- Teets, J.C., Hurst, W. (2014). 'Introduction: The politics and patterns of policy diffusion in China', in: Teets, J. C., Hurst, W. (ed.) *Local Governance Innovation in China: Experimentation, Diffusion, and Defiance*, 1st ed. Taylor and Francis, pp.1-24 <https://doi.org/10.4324/9781315796819>
- Teets, J.C., (2014). *Civil Society under Authoritarianism: The China Model*. Cambridge: Cambridge University Press. <https://doi.org/10.1017/CBO9781139839396>
- The Chinese Hospital Association (2019) *The Chinese Hospital Association Launches Patient Safety Objectives* (2019). Available at: <http://www.cha.org.cn/plus/view.php?aid=15808> (Accessed: 15 June 2020).
- The Leapfrog Group (n.d.) *Errors, Injuries, Accidents, Infections*. Available at: <https://hsg-stage.workcenter01.atlasworks.com/what-is-patient-safety/errors-injuries-accidents-infections> (Accessed: 15 June 2020).
- Thompson, A., (1999). 'Editorial. New millennium, new values: citizen participation as the democratic ideal in health care'. *International Journal for Quality in Health Care* 11, 461–464.
- Thompson, A.G.H., (2007). 'The meaning of patient involvement and participation in health care consultations: A taxonomy'. *Social Science & Medicine* 64, 1297–1310. <https://doi.org/10.1016/j.socscimed.2006.11.002>
- Thompson, A.G.H., (2020). 'Contextualising co-production and co-governance in the Scottish National Health Service'. *Journal of Chinese Governance* 5, 48–67. <https://doi.org/10.1080/23812346.2019.1689035>
- Thompson, A., Ruusuvuori, J., Britten., N.,& Collins., S.(2007). 'An integrative approach to patient participation in consultations'. In: Collins., S., Britten., N., Ruusuvuori., J., and Thompson., A.(ed.) *'Patient Participation in Health Care Consultations'*, UK: Open University Press, pp. 176-192.
- Traianou, A., (2014). 'The Centrality of Ethics in Qualitative Research', in: Leavy, P (ed.), *The Oxford Handbook of Qualitative Research*, Oxford University Press, Incorporated, Cary, pp. 62-77. Available from: ProQuest Ebook Central. [8 January 2021].
- Tritter, J.Q., (2009). 'Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world'. *Health Expectations* 12, 275–287. <https://doi.org/10.1111/j.1369-7625.2009.00564.x>
- Tsang, S., (2016). 'Consolidating Political and Governance Strength', in: Tsang, S., Men, H. (ed.), *China in the Xi Jinping Era*. Cham: Springer International Publishing: Imprint: Palgrave Macmillan, pp. 17–40. https://doi.org/10.1007/978-3-319-29549-7_2
- Wagenaar, H., (2007). 'Governance, Complexity, and Democratic Participation: How Citizens and Public Officials Harness the

- Complexities of Neighborhood Decline'. *The American Review of Public Administration* 37, 17–50.
<https://doi.org/10.1177/0275074006296208>
- Walliman, N., (2006). Qualitative Data Analysis., in Walliman, Nicholas. (ed.), *Social Research Methods*. England, London: SAGE Publications, Ltd., pp.129–147. <https://doi.org/10.4135/9781849209939>
- Wang, Hufeng, Gusmano, Michael K & Cao, Qi, (2011). An evaluation of the policy on community health organizations in China: Will the priority of new healthcare reform in China be a success? *Health policy (Amsterdam)*, 99(1), pp.37–43.
- Wang, Q., Zhang, D., Hou, Z., (2016). 'Insurance coverage and socioeconomic differences in patient choice between private and public health care providers in China'. *Social Science & Medicine* 170, 124–132. <https://doi.org/10.1016/j.socscimed.2016.10.016>
- Wank, D.L., (1999). *Commodifying communism: business, trust, and politics in a Chinese city, Structural analysis in the social sciences*. Cambridge: Cambridge University Press.
- Webb, S., Webb, B., (1975). *Methods of Social Study*. Cambridge University Press.
- Wellman, B., Chen, W., Dong, W., (2002). 'Networking Guanxi'. In: Gold, T., Guthrie, D., Wank., D. (ed.), *Social Connections in China: Institutions, Culture, and the Changing Nature of Guanxi.*, Cambridge: Cambridge University Press, pp. 221–241. Available from: ProQuest Ebook Central. [10 December 2020].
- Weltbank (Ed.), (1997). *The state in a changing world, 1. print. ed, World development report*. Oxford: Oxford Univ. Press.
- Whitaker, G.P., (1980). 'Coproduction: Citizen Participation in Service Delivery'. *Public Administration Review* 40, 240.
<https://doi.org/10.2307/975377>
- Wilson, M., Sapsford, R.,(2006). Asking Questions, in: Sapsford, R., Jupp, V., (ed). *Data collection and analysis, Second edition*. Los Angeles; London: SAGE Publications in association with the Open University, pp. 93–123. <https://dx-doi-org.ezproxy.is.ed.ac.uk/10.4135/9781849208802.n4>
- Winterbottom, A., Bekker, H.L., Conner, M., Mooney, A., (2008). 'Does narrative information bias individual's decision making? A systematic review'. *Social Science & Medicine* 67, 2079–2088.
<https://doi.org/10.1016/j.socscimed.2008.09.037>
- World Health Organization (ed.), (2000). *The World Health Report 2000: health systems: improving performance*. WHO, Geneva.
- World Health Organisation (2004) *Declaration of Alma-Ata*. Alma-Ata: Available
at: https://www.who.int/publications/almaata_declaration_en.pdf (Accessed: 15 June 2020).
- Wyke, S., Entwistle, V., France, E., Hunt, K., Jepson, R., Thompson, A., Ziebland, S.B., (2011). *Information for choice: what people need, prefer and use*. Report for the National Institute for Health Research Service Delivery and Organisation programme.
- Xue, L., Zhong, K., (2012). 'Domestic reform and global integration: public administration reform in China over the last 30 years'. *International Review of Administrative Sciences* 78, 284–304.
<https://doi.org/10.1177/0020852312438784>
- Yang, G., (2005). Environmental NGOs and Institutional Dynamics in China. *The China quarterly (London)*, 181(181), pp.46–66.
- Yeh, M.-Y., Wu, S.-C., Tung, T.-H., (2018). 'The relation between patient

- education, patient empowerment and patient satisfaction: A cross-sectional-comparison study'. *Applied Nursing Research* 39, 11–17. <https://doi.org/10.1016/j.apnr.2017.10.008>
- Yin, R.K., (2014). *Case study research: design and methods, Fifth edition*. Los Angeles: SAGE.
- Yip, W., Hsiao, W.C., (2015). 'What Drove the Cycles of Chinese Health System Reforms?' *Health Systems & Reform* 1, 52–61. <https://doi.org/10.4161/23288604.2014.995005>
- Yip, W.C.-M., Hsiao, W.C., Chen, W., Hu, S., Ma, J., Maynard, A., (2012). 'Early appraisal of China's huge and complex health-care reforms'. *The Lancet* 379, 833–842. [https://doi.org/10.1016/S0140-6736\(11\)61880-1](https://doi.org/10.1016/S0140-6736(11)61880-1)
- Yu, J., Guo, S., (2012). *Civil society and governance in China*. Palgrave Macmillan.
- Zhang, Anwen, Nikoloski, Zlatko & Mossialos, Elias, (2017). Does health insurance reduce out-of-pocket expenditure? Heterogeneity among China's middle-aged and elderly. *Social science & medicine* (1982), 190, pp.11–19. <https://doi.org/10.1016/j.socscimed.2017.08.005>
- Zhang, X., Sleeboom-Faulkner, M., (2011). 'Tensions between Medical Professionals and Patients in Mainland China'. *Cambridge Quarterly of Healthcare Ethics* 20, 458–465. <https://doi.org/10.1017/S0963180111000144>
- Zhang, X-H., Lu, Z. L., & Liu, L. (2008). 'Coronary heart disease in China'. *Heart*, 94 (9), 1126-1131.
- Zhao, S. (2017) *Chen Zhu: Promoting the Reform of 'Joint Reformation for Three Medical Services' and Making Breakthrough of Intersectoral Benefits*. Available at: https://www.thepaper.cn/newsDetail_forward_1923978 (Accessed: 16 June 2020).
- Zheng, Y., (2007). *De Facto Federalism in China: Reforms and Dynamics of Central-Local Relations*. Singapore: World Scientific.

Appendices

Appendix 1 Interview outline (patients)

Individual attributes:

Gender: woman/man

Age: How old are you?

Type of Patient: Are you inpatient or outpatient?

Type of disease: What conditions do you have: chronic or acute disease?

Socioeconomic status: What type of health insurance do you have?

Perceived seriousness: How do you feel about your condition? Is it serious or not?

Clinical department: Which clinical department are you in?

Origin of patient: Do you go to the hospital directly or referred from other hospitals?

The cultural context:

Education: your educational background; do you have any qualifications or certificates in health care?

Exposure to written materials and mass media in relation to health care: How often do you read books, newspapers, magazines or watch TV that are relevant to health and health care?

Use of the internet in relation to health care: Can you use the internet to search information? How often do you use it in relevant to health and health care?

The social context:

Carer Details: Do you have anyone who take care of you when you are ill? What kind of support do you get from them?

Family Involvement: Who is involved in your health care? Are you happy with it? Do you need to ask your spouse/siblings to make decisions? If so, why do you think you should ask them?

Social network and resources: relatives or friends working in health system and offering advice and support; use of patient network (online/offline)

Views of health system:

Reasons for the choice of health facility: Why you choose this hospital?

Mechanism of involvement: If you are not happy with the health services in the hospital, what would you do?

Relationship of professionals and patients:

Some people talk about the importance of trust in their doctors, while others do not. Is it an issue for you?

What do you think the ideal patient-doctor relationship would be? Any differences of the relationship between an ideal model and in reality? Do you think your doctor is professional?

Do you think you have an equal relationship with your professionals?

Opinions of current system: How do you view the current health service delivery? What are your major concerns over health care? Are you happy with health services you have now? How do you like the marketised health system now? Have you experienced planned health care in the past?

Involvement in health care:

Can you share your experience of engaging with health professionals in the treatment process?

Have you got any ideas of your condition before the treatment? Any ideas of how to be treated?

Do you like talking with your doctor about your condition and treatment?

Do you think you can express clearly about how you feel and your need?

Do you understand the interventions the doctor has had on you in the process of treatment?

Will you make any suggestions or proposals to the health authority and the hospital, in order to improving service quality, if there are any?

Do you feel positive or negative when the doctor gives you several options of treatment?

If there is any bad news, do you want to know it? Will someone come over to tell you, and who would you prefer?

Desire for involvement:

Information:

Do you want to learn more about your condition and treatment options? Do you think you have got enough information?

Decision-making:

Who makes the decisions for your treatment?

Do you want to leave decision-making to professionals?

Why do you/why not involve professionals in health care decisions?

To what extent do you wish to be involved in health care delivery? What kind of discussion do you want to be involved in the process of health care?

Chinese version

个人特征：

1. 性别：女/男
2. 年龄：您今年多大了？
3. 病人类型: 住院病人/门诊病人
4. 疾病类型：急性病/慢性病
5. 社会经济状况：您有哪种类型的医疗保险？
6. 感知的严重程度：您感觉您的病情严重吗？
7. 您所在的科室
8. 病人来源：您是直接在此院就医还是从其他医院转诊的？

文化资源：

教育程度：您的教育程度；您有与医疗护理有关的学历证书或从业资格证吗？

大众传媒和书籍的接触频率：您平时阅读与健康相关的报刊杂志、书籍或观看这类电视节目吗？多久阅读或观看一次呢？

互联网的使用频率：您会上网吗？您平时上网浏览与健康有关的信息吗？多久使用一次网络查询健康信息？

社会资源：

看护情况：您患病期间有人照顾您吗？从他们那里得到了什么样的支持和帮助？

家庭参与：关于您的治疗，家人有没有参与？您对此感到高兴还是不满意？您需要配偶/子女帮忙做决定吗？如果是，为什么需要询问他们的意见和看法？

社会网络资源：您有学医或者从事医务工作的亲朋好友吗？他们在您看病的过程中有没有帮助您或给您过好的建议？您有没有接触到其他病人群体（网络/现实）？

对医疗体系的看法：

选择就医机构的原因：为什么选择这所医院？

参与医疗服务的机制：如果您不满意医院的服务，您会怎么做？

医患关系：

有的人认为病人对医生的信任非常重要，有的人认为不重要。您怎么看待这件事情？

理想状态下，您认为医生和患者的关系应该是怎么样的？现实中的医患关系怎么样？理想和现实有差别吗？您觉得您的主治医生的水平怎么样？

您觉得您和医生的关系平等吗？

对现有医疗体系的看法：您怎样看待现在的医疗服务？您最关心医疗服务方面的什么问题？您对现在的医疗服务满意吗？您喜欢计划经济时期的医疗体制，还是现在的市场经济时期的医疗体制？您经历过计划经济时期的医疗体制吗？

参与医疗护理：

您能分享一下治疗过程中您与医生互动的经历吗？

来医院治疗前，您知道自己的病情吗？您知道该怎么治疗吗？

您喜欢与医生讨论您的情况和治疗方案吗？

您感觉自己能清楚的表达您的状况和需要吗？

您能理解医生进行的治疗措施吗？

如果对医疗服务有建议，您愿意反映给卫生部门或医院吗？

当您的医生告诉您治疗方案的选择，您感觉积极还是消极？

如果有坏消息，您想知道吗？您想让谁来告诉您？

参与医疗服务的意愿：

信息：

您愿意对自己的情况和治疗方案有更详细的了解吗？您觉得现在获取的信息足够满足您的需要吗？

决策：

谁可以决定您的治疗方案？

您想把治疗的决定权留给医生吗？为什么（不）想留给医生做决定？

在治疗方案的选择上，您多愿意参与医疗决策吗？多大程度上参与？您愿意了解参与哪些环节的讨论？

Appendix 2 Interview outline (professionals)

1. Understanding of patient involvement and participation :

Could you talk about your understanding regarding it?

Do you think involving patients is important in service delivery?

How do you involve patients in the process of health care delivery?

2. Actual involvement at the clinical level:

Do patients value information of their conditions and treatments in their health care?

Do they want to know any information from professionals and what kinds of information are they interested in?

According to your experience, do patients prefer to be involved in decision-making or ask you to do it instead?

What kinds of patients prefer what types of decision-making?

What would you do if you meet those who do not want to make any decisions?

In which circumstances do their families involved?

Do you have any priority to involve patients or lay carers?

Who do you want to include in the discussion, the patient or the family member?

3. Policies regarding patient involvement and participation:

Are there any policies regarding the issue?

Are there any regulations regarding involving patients in their health care in the hospital?

What do you think of informed consent? Is it an effective approach to involve users?

4. Professional-patient relationship:

What do you think of the professional-patient relationship in China? Do you think it is related to how much patients involved in their health care?

Chinese version

1. 针对“患者参与诊疗”的理解：

您能谈谈对这个概念的理解吗？在医疗服务的过程中，您觉得患者的参与重要吗？体现在哪些方面和环节？（您平时鼓励患者和家属参与到诊疗过程中来吗？）

2. 实际参与诊疗的情况：

病人对自己的病情和治疗方案等信息重视吗？他们想要从医生这里了解哪些信息？根据您个人的工作经验，病人喜欢参与他们的医疗护理决策过程吗？在您遇到的病人中，哪些更倾向于让您替他们选择方案，哪些愿意跟您讨论参与到这个过程？（有没有遇到那种需要医生帮助做决定的病人？这样的情况下您一般怎么处理？）在什么情况下家属要参与进来？家属和病人的参与，医生有没有优先顺序？

3. 患者参与诊疗的政策：

在“患者参与诊疗”方面，国家有没有相关政策跟进？医院有没有相关规定确保患者参与诊疗？您觉得知情同意这个制度怎么样？有没有效果？

4. 医患关系：

您感觉国内现在医患关系怎么样？您觉得医患关系与患者的参与程度较有关系吗？

Appendix 3 Interview outline (health board managers)

1. What kinds of health projects have you involved in the recent years? What is it for? Which department(s) are involved in?
2. Could you talk about the progress of the projects? What problems have you met?
3. Talk about your understanding of health facilities and service providers.
4. Do you think patients as service users are passive or active in health care delivery?
5. Do you think patients are important in the service delivery?
6. Do you think patients should have a say in health policy-making?
7. Do you think patients should have a say in health service management?
8. What do you think is the biggest obstacle to health service delivery in China?

Chinese version

1. 请问您最近几年负责了什么医疗（服务）项目？针对哪些人群？这个项目由哪个（些）部门负责？
2. 您能否谈谈项目的实施效果如何？在项目实施过程中遇到了哪些问题？
3. 请谈谈您对医疗机构和服务机构的理解。
4. 在您的认识中，病人作为服务使用者在医疗服务中是主动的还是被动的？
5. 您感觉，病人在自己的诊疗过程中的地位重要吗？
6. 您觉得，病人应该对医疗政策的制定有发言权吗？
7. 您觉得，病人应该对医院的服务和管理有发言权吗？
8. 您认为，当前我国在提供医疗服务的过程中遇到的最大问题是什么？

Appendix 4 Interview outline (local administrators)

Appendix 4.1 Local administrators from health authority

1. Are there any progress of policy-making regarding patient rights and involvement in health care delivery? And laws and regulations?
2. In what aspects could patient rights be ensured by policies and legislation?
3. What measures are there regarding quality control at the policy and organisational levels? Are these measures taken into considerations of roles of patients and lay carers?
4. Please talk about the recent health reforms and the policy emphases and outcomes.
5. What roles do local governments play in health policy-making? Do you have power of policy-making and service planning?
6. Are the voices of patients and lay carers included in policy-making and implementation? Have you considered any marginalised groups during policy-making process?
7. Are there any existing approaches and procedures for patients and their family members to make complaints?
8. How can voices of the public be ensured in the process of policy-making?
9. Are there any forums of gathering patients preferences and views to help with decision-making and service planning at the local level?
10. How is the evaluation of patient satisfaction implementing at the local level?
11. Any recent initiatives of improving professional-patient relationship at the provincial level?
12. The current state of play of financial budget on health care at the state level.

Chinese version

1. 在患者权利和患者参与方面有没有政策上的进展？在保障病人权利方面，有哪些法律提供保障？
2. 患者的权利表现在哪些方面？
3. 在政策层面和机构层面，质量控制有哪些举措？有没有考虑到患者和家属的作用？

4. 谈谈目前医改的情况，比如侧重点和效果。
5. 地方政府在医改过程中有没有制定政策的权力？有哪些？
6. 当前医疗政策制定和执行过程中，病人和家属是什么地位？有没有考虑到一些特殊的人群，制定适合他们的政策？
7. 有没有相应的机制和渠道保障病人和家属的投诉畅通？
8. 政策制定过程中怎样最大范围的反映民意？
9. 有没有建立患者论坛一类的机制来帮助地方政府制定政策和规划医疗资源？
10. 地方政府关于患者的满意度考核是如何执行的？
11. 在省级政府层面，对改善医患关系采取了哪些行动？
12. 近年来，国家对医疗卫生事业的财政投入情况如何？

Appendix 4.2 Local administer from authority of civil affairs

1. How does the local government regulate social organisations in the recent years?
2. Why is there a distinction of social communities (shetuan), non-profit enterprises (minbanfeiqiyezuzhi) and charity foundations (jijinhui)?
3. Is it strict regarding the regulations of social organisations? What measures are there to regulate social organisations at the local level?
4. Why do you monitor the progress of party-building activities of these organisations?
5. Talk about the current state of play of purchasing social services.
6. Are there any specific funding to support the development of social organisations?
7. What is the trend of social organisations in this city? Are there different types of social organisations?
8. Are there still any GONGOs now?

Chinese version

1. 近年来政府对社会组织的管理情况如何？
2. 社团、民非和基金会为什么要进行分类管理？
3. 政府对社会组织的管理一直都很严格吗？现在对于监管采取怎样的措施？
4. 为什么要考察社会组织的党建活动？
5. 请谈谈政府购买服务的情况。
6. 为什么需要设立专项资金来扶持社会组织的发展？
7. 目前您所在的管辖范围内社会组织都有哪些类型，数量上是怎样的趋势？
8. 现在还存在官办的社会组织吗？

Appendix 5 Informed consent (patients)



THE UNIVERSITY of EDINBURGH
School of Social and
Political Science

zhujingyanuo@163.com

Patient Involvement and Participation in Health Care Delivery

Dear Participant,

My name is Jingyan Zhu, and I am a PhD candidate in Political and Social Science in Edinburgh University. Approved and supported by the hospital administration, I would conduct my research '**Patient Involvement and Participation in Health Care Delivery**' recently. The study aims to explore the factors, meanings and processes of patient involvement in the health service delivery, particularly in information giving/seeking and treatment decision-making. The research is intended to provide objective and scientific research evidence in this field, and promote patient involvement in the process of health services, as well as improve health service quality.

Your participation is completely voluntary. Please read the information below. If you AGREE with it, please continue. If you are not patient who receives medical treatment, please DO NOT take part. If you have already participated, please DO NOT answer questions again.

I take part voluntarily in the research project conducted by Jingyan Zhu in the University of Edinburgh. I understand the objectives and aims of the research: obtaining relevant data of '**Patient Involvement and Participation in Health Care Delivery**'.

I understand my participation is voluntary, and I would not gain any payment in any forms. If I deny taking part or quit the interview halfway, there will not be any negative influence on it.

I understand if I feel any uncomfortable during the interviewing, I have the rights to refuse to answer any questions or end the interview. The interview

includes 6 themes and will last 20 minutes in total.

I understand that the interview would be recorded to collect data conveniently.

I understand that the research will not mention my personal information in any reports when use information that are relevant to the interviews. As a participant, my privacy will be protected. If I offer my e-mail address, I would permit the research a return interview in the spring of 2017.

I permit the data of the interviews to use for research purpose. The data use will follow relevant polices and regulations of Edinburgh University, and be protected anonymously.

I have read and understand the items above. I have fully understood and happy with questions above. I will take part in the research voluntarily.

Chinese translation

病人参与医疗服务过程的研究

尊敬的病人，我是朱靖琰，是英国爱丁堡大学政治与社会科学学院博士候选人。现经过贵院的同意和支持，开展关于“病人参与医疗服务过程”的研究。此研究致力于探索病患在参与医疗决策过程中的实际意义、影响因素和过程，为病患参与医疗服务提供更客观科学的研究证据，充分促进患者参与临床决策的过程，提高医疗服务质量。

您的参与完全出于自愿性。请阅读以下信息，如果您同意以下内容请继续。如果您不是接收医疗服务的患者，请不要参与访谈。如果您已经参与过访谈，请不要再次回答。

我自愿参与由爱丁堡大学的朱靖琰主持的研究课题。我理解该访谈的目的是为了获取“病人参与医疗服务过程的研究”的相关数据。

我理解我的参与纯属志愿性，并且不会获得任何形式的报酬。如果我拒绝参与或者中途退出访谈，不会产生任何负面影响。

我理解如果在访谈过程中有任何感觉不舒服的地方，我有权拒绝回答任何问题或者终止访谈。访谈主要包括 6 大主题，大约持续 20 分钟左右。

我理解为了方便数据收集，访谈将被录音。

我理解研究者在任何报告中使用该访谈有关的信息时不会提到我的名字，作为一名参与者，我的隐私将会受到保护。如果我提供电子邮箱，我会允许朱靖琰在 2017 年春天进行回访。

我允许访谈数据可以作为研究使用。数据的使用将会遵照爱丁堡大学相关数据使用的政策，对其进行匿名保护。

我已阅读并理解以上条款。我已经充分理解并且满意以上问题，我将自愿参与此项研究。

Appendix 6 List of interviews of other stakeholders

Interview 1: The interviewee is a local health administrator. He serves as Director of a department in the provincial health authority when the interview is conducted. He is responsible for planning health resources and services, making regulations of quality and safety of care in the province. He is also responsible for monitoring and evaluating quality performance of public hospitals.

Interview 2: The interviewee is a local health administrator, who serves as the Associate Director of a department in the provincial health authority. It is not clear about his roles/responsibilities in the department, but he is in the same department with interviewee 1.

Interview 3: He is a surgeon in the Department of Urinary Surgery in Case 2. He mentioned in the interview that he had a PhD degree.

Interview 4: She is a physician in the Department of Cardiology in Case 1.

Interview 5: She is a physician in the Department of Endocrinology in Case 3. She mentioned in the interview that she had a master's degree.

Interview 6: He is a surgeon in Department of Emergency in Case 2.

Interview 7: She is a physician in Department of Breast Cancer in Case 3.

Interview 8: He is a surgeon in Department of Breast Surgery in Case 1. He mentioned in the interview that he had a PhD degree.

Interview 9: She is a middle-aged manager, serving as Director of a department in Case 3. She is responsible for managing preventive health services in the county hospital. She implements state and local policies regarding preventive services, controlling and monitoring communicable diseases and conducting activities of health promotion and education.

Interview 10: He is a middle-aged manager, who serves as Director of a department in Case 3. He has a master's degree. He is working on preventing and controlling infectious diseases in the county hospital. He works specifically on the techniques of controlling and monitoring bacteria at the clinical and management levels. He is responsible for providing training sessions of infectious disease management within the hospital. He is also a surgeon for years.

Interview 11: She is a middle-aged, serving as Director of a department in Case 2. She is responsible for planning health resources and services in the fields of antenatal care and baby development in the hospital. She is also responsible for health promotion and education to women who are pregnant and breastfeeding.

Interview 12: He is a retired manager, who used to be the Former Associate Dean in Case 2.

Interview 13: He is a middle-aged manager, who serves as Director of a department in Case 1. He is responsible for responding medical disputes and complaints to service users. He is also responsible for supervising professionals' behaviours in the clinical practice.

Interview 14: She is a middle-aged manager, serving as Director of a department in Case 3. She has a master's degree. She is responsible for recruiting health staff and organising training sessions.

Interview 15: She is a middle-aged manager, who serves as Director of a

department in Case 1. She has a master's degree. She works on improving quality of care in the hospital. She drafts quality control regulations and revises them every three years. She is also dedicated to promoting effective improvement strategies in some clinical departments, such as Cardiology Department. She also mentions about initiatives of patient involvement in patient safety, which are carried out among patients with chronic conditions.

Interview 16: He is an academic in a local university. He is an expert in public policy, public service reforms and central-local relations.

Interview 17: She is an academic in a local university. She is an expert in civil society organisations and contracting to NGOs in the public service sectors.

Interview 18: He is an academic in a local university. He is an expert in health system reforms in China.

Interview 19: She is a local administrator in the Bureau of Civil Affairs in Jinan. She serves as the administrator of a department in the Bureau. Her roles include the sponsorship of social organisations registration in the city. She is also responsible for supervising and evaluating social organisations.

Interview 20: She is a leader of a health-related NGO, who works for years in the organisation. The NGO is called China-Dolls Centre for Rare Disorders. It is dedicated to providing support for patients with rare disorders. It is also working on policy advocates, trainings and psychological counselling for patient groups. China-Dolls has been very successful in raising funds and offering medical aids since it was born in 2008. The interviewee is working for the sub-branch of the organisation in Shandong Province when the interview is conducted. She has been working as a campaign leader and social worker.